S. Hrg. 98-1083 Pt. 3

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1985

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

ON

H.R. 6028/S. 2836

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1985, AND FOR OTHER PURPOSES

Part 3—(Pages 1-716)
Congressional Witnesses
Nondepartmental Witnesses

Printed for the use of the Committee on Appropriations

U.S. GOVERNMENT PRINTING OFFICE
32-377 O
WASHINGTON : 1984

S181-12

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

LOWELL P. WEICKER, JR., Connecticut, *Chairman*

MARK O. HATFIELD, Oregon
TED STEVENS, Alaska
MARK ANDREWS, North Dakota
WARREN RUDMAN, New Hampshire
ARLEN SPECTER, Pennsylvania
JAMES A. McCLURE, Idaho
PETE V. DOMENICI, New Mexico

WILLIAM PROXMIRE, Wisconsin
ROBERT C. BYRD, West Virginia
ERNEST F. HOLLINGS, South Carolina
THOMAS F. EAGLETON, Missouri
LAWTON CHILES, Florida
QUENTIN N. BURDICK, North Dakota
DANIEL K. INOUYE, Hawaii

Majority Professional Staff

CLAUDIA INGRAM, GAR KAGANOWICH, RIKI POSTER SHEEHAN, CAROL ORTEGA, JAMES J. SOURWINE, and STEVEN BONGARD

Minority Professional Staff

TOM VAN DER VOORT and MARION R. MAYER

Administrative Support

TERRY L. MUILENBURG, NANCY C. ANDERSON, PATRICIA F. FALSEY, and BARBARA L. RHODEN

CONTENTS

WEDNESDAY, APRIL 11, 1984

Page

Congressional witnesses 1
Nondepartmental witnesses 39

THURSDAY, APRIL 12, 1984

Nondepartmental witnesses 249

TUESDAY, APRIL 24, 1984

Nondepartmental witnesses 475

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1985

WEDNESDAY, APRIL 11, 1984

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker, Rudman, and Inouye.

CONGRESSIONAL WITNESSES

STATEMENT OF HON. PAUL S. TRIBLE, U.S. SENATOR FROM VIRGINIA

ACCOMPANIED BY:
- DR. HARRISON WILSON, PRESIDENT, NORFOLK STATE UNIVERSITY
- DR. DAVID T. SHANNON, PRESIDENT, VIRGINIA UNION UNIVERSITY
- DR. WILBERT GREENFIELD, PRESIDENT, VIRGINIA STATE UNIVERSITY
- DR. OSCAR PRATER, VICE PRESIDENT OF ADMINISTRATION, HAMPTON INSTITUTE

OPENING REMARKS

Senator RUDMAN [presiding]. We will bring the subcommittee to order. The chairman of the subcommittee is detained on other business this morning. So I will be chairing the first half hour this morning, and then our colleague, Senator Inouye of Hawaii, will be coming at 9:30 to continue with the hearing.

This morning we're delighted to have in front of us our colleague from Virginia, Senator Paul Trible. He's accompanied by some gentlemen I'm going to let him introduce, who are the presidents and officers of institutions of higher education in the State of Virginia.

We have a little time system here, gentlemen. The way it works is when the green light goes on, that means you've started your statement and then you have 4 minutes or so to testify. When you see the red light go on, we would like you to end your statement.

We have a long list of public witnesses this morning and we'll have to have a little discipline. My friend, Paul Trible, if you would like to introduce your witnesses and proceed in any order that you like. At this time, your complete statement along with those accompanying you will be made a part of the record.

[The statements follow:]

STATEMENT OF SENATOR PAUL TRIBLE

The diversity of our colleges and universities has contributed markedly to America's economic, educational, and cultural well-being.

One significant element in this rich cultural fabric is in jeopardy. America's historically black colleges and universities are threatened by rising costs and declining enrollments. These institutions have produced generations of leaders, fostered a sense of identity and community, and met the needs of the economically disadvantaged.

We must insure the continued vitality of these institutions. In Virginia, Norfolk State University, Virginia Union University, Virginia State University, and Hampton Institute offer exemplary educational opportunities and they must continue to do so.

Congress and the administration have responded to this critical situation. Last year the funding for aid to historically black colleges was increased and it is my hope that adequate funding will again be available this year.

STATEMENT OF HARRISON B. WILSON

Finance has been the No. 1 problem of historically black colleges from their founding. The reason for their existence was to provide educational services to the minority population of this country, which had little or no funds to pursue the privilege of higher education. Now that these institutions have survived and are attempting to compete in the mainstream of higher education, financial burdens continue to mount.

Norfolk State University, a public urban institution of higher education, encounters financial needs in several areas of which the Federal Government might be of major assistance. Funds are needed to:

1. Provide additional grant money in the form of financial aid assistance for low-income students based on need—giving students the opportunity to attend college.
2. Provide Federal funds for research grants in black colleges and universities.
3. Increase library collections and holdings to meet the needs of old, new, and projected programs.
4. Hire more doctorally qualified faculty in critical academic areas.
5. Increase the retention of students through developmental and remedial programs.
6. Continue enhancing the facilities of the instituion to accommodate present and new programs and maintenance of same.
7. Maintain adequate management techniques—add more qualified support staff.
8. Support for outreach programs—further project the services of this university into the community, the State, and the Nation.
9. Provide expanded faculty development program activities—research, educational leaves.
10. Funds to develop a positive image of the university—provide stronger visibility, enhance admissions procedures, improve recruitment methods to meet the competition.
11. Subsidize the rising costs for essentials due to inflationary spiral—electricity, fuel, maintenance costs.
12. Funds to enahnce the development operations—develop a good multifaceted program; diversify the solicitation of funds (additional sources); scholarship capitalization funding; and computerization of fundraising process.

Statement of William R. Harvey, President, Hampton Institute

BLACK COLLEGES PRIMARILY SERVE BLACK STUDENTS. THE STUDENT POPULATION SERVED IN THE PAST, PRESENTLY BEING SERVED, AND WHO WILL BE SERVED IN THE NEAR FUTURE ACTS AS THE DRIVING FINANCIAL FORCE THROUGH WHICH BLACK COLLEGES ARE PRIMARILY SUPPORTED. TO ASSESS THE FINANCIAL BARRIERS FACING BLACK COLLEGES THEN IS TO ASSESS THE ECONOMIC STATUS OF THE ABOVE STUDENT GROUPS FOR IT IS THEIR ABILITY TO PAY TUITION AND FEES AT THE LEVEL NEEDED, THEIR ABILITY TO SUPPORT THESE COLLEGES FINANCIALLY THROUGH ALUMNI CONTRIBUTIONS AT THE LEVEL NEEDED, AND THEIR ABILITY TO OBTAIN POSITIONS OF INFLUENCE WITH PRIVATE AND GOVERNMENTAL FUNDING SOURCES IN SUFFICIENT QUANTITIES THAT DETERMINE THE FINANCIAL CONDITIONS THESE INSTITUTIONS MUST FACE.

BRIEFLY, I WOULD LIKE TO REVIEW PERTINENT STATISTICS RELATIVE TO THIS POPULATION GROUP, WHICH WILL REFLECT THE CONTENTIONS PREVIOUSLY NOTED, AND CONCLUDE WITH THE BENEFITS RECEIVED FROM PAST SUPPORTED ACTIVITIES AND SUMMARIZE.

UNEMPLOYMENT HAS REMAINED HIGH WITHIN THE BLACK COMMUNITY. IN 1982, THE UNEMPLOYMENT RATE FOR BLACKS WAS 18.9%, 14.5% HIGHER THAN THAT FOR THE WHITE POPULATION. DURING THIS SAME PERIOD, UNEMPLOYMENT FOR TEENAGE BLACKS REACHED THE STAGGERING LEVEL OF 40.9%.

Another indication of the economic health of the Black population is the wages earned. During 1983, a total of 160.5 billion dollars were earned by Blacks, representing 7.5% of all wages earned, a disproportionately small amount when compared to the racial composition of the total population.

The number of Black families with children living below the poverty level rose from 34.9% in 1970 to 35.6% in 1980. During the same period, the number of Black females heading households increased. The median income of these households is $7,458; 36% less than the $20,586 earned by Black married couples. From this brief portrait of economic disparity, one can better understand how economic conditions impact upon the ability of the Black community to support Black institutions.

It is with assistance from Federal agencies and other sources that these institutions have been able to reach their present levels of success. I would like to illustrate this point by personal example, if I may.

Since its inception at Hampton Institute, the Title III (Institutional Aid) Program has impacted every segment of the college: the academic program, student services, faculty and staff development, administrative and management functions. We have developed and fully implemented a long-range planning process, and an institutional research program that provides

A SOUND BASIS FOR POLICY DEVELOPMENT, DECISION MAKING AND CONTINGENCY PLANNING.

WE ARE INSTITUTING A COLLEGE-WIDE MANAGEMENT INFORMATION SYSTEM THAT WILL STRENGTHEN OUR ABILITY TO EFFECTIVELY MANAGE AND OPERATE THE ADMINISTRATIVE, ACADEMIC AND SUPPORT AREAS WHICH MAKE UP THE TOTAL INSTITUTION. WE HAVE IMPROVED THE COLLEGE'S FUND RAISING CAPACITY THROUGH STAFF DEVELOPMENT, PUBLIC RELATIONS PROGRAMMING, ALUMNI INVOLVEMENT AND THE PERSONAL LEADERSHIP OF THE COLLEGE PRESIDENT.

WE HAVE DEVELOPED NEW ACADEMIC PROGRAMS IN RESPONSE TO THE CHANGING NEEDS OF OUR CONSTITUENTS, AND HAVE STRENGTHENED EXISTING PROGRAMS TO MAINTAIN THEIR RELEVANCE TO CURRENT EDUCATIONAL REQUIREMENTS. WE HAVE PROVIDED FACULTY OPPORTUNITIES TO "RETOOL," "RETRAIN," OR TO IMPROVE THEIR ABILITY TO TEACH IN GENERAL. STUDENTS HAVE BEEN ASSISTED IN THEIR ADJUSTMENT TO COLLEGE VIA ACADEMIC AND PERSONAL COUNSELING PROGRAMS CONDUCTED BY A STAFF THAT HAS BEEN TRAINED TO PROVIDE APPROPRIATE AND EFFECTIVE STUDENT SERVICE PROGRAMS. IT HAS BEEN DUE TO THE SUPPORT OF THE FEDERAL GOVERNMENT, THROUGH GIFTS AND GRANTS, THAT THESE VERY POSITIVE STRIDES HAVE BEEN MADE.

OF OUR TRADITIONAL SOURCES OF REVENUE (STUDENTS, GIFTS AND GRANTS, AND ENDOWMENT INCOME), STUDENTS ARE BEING ASKED TO CONTRIBUTE AN INCREASINGLY LARGER PERCENTAGE OF THE COST OF

THEIR EDUCATION. GIVEN THEIR ECONOMIC BACKGROUND, THE FINANCIAL BURDEN WORKS TO DENY THESE STUDENTS AN EQUAL OPPORTUNITY TO PURSUE HIGHER EDUCATION. THUS, HAMPTON INSTITUTE AND OTHER BLACK COLLEGES AND UNIVERSITIES WILL NEED THE CONTINUED AND IMPROVED SUPPORT OF THE FEDERAL GOVERNMENT.

THESE INSTITUTIONS DO NOT HAVE THE RESOURCES REQUIRED TO ROUTINELY ADVANCE THEIR PROGRAMS, FACILITIES AND PHYSICAL PLANTS IN KEEPING WITH THE RAPID CHANGES BEING MADE IN OUR SOCIETY. TECHNOLOGY IS VITAL TO THE CONTINUED GROWTH OF THIS COUNTRY; YET, ITS COST IS INORDINATELY HIGH AND IN MOST INSTANCES PROHIBITIVE FOR THE MINORITY INSTITUTION THAT IS EXPERIENCING ENROLLMENT DECLINES IN A STUDENT BODY THAT CAN NO LONGER AFFORD THE HIGH COST OF A COLLEGE EDUCATION.

I WILL NOT INSULT THE INTELLIGENCE OF THE COMMITTEE BY REPEATING THE ROLE BLACK COLLEGES HAVE PLAYED IN THE GROWTH OF THIS NATION. FOR I AM SURE THAT YOU HAVE HEARD THESE FACTS NUMEROUS TIMES. I WILL REPEAT, HOWEVER, THAT THESE COLLEGES ARE A VALUABLE RESOURCE TO THIS NATION, ONE THAT THE COUNTRY CAN ILL AFFORD TO LOSE.

TO CONTINUE THE PROGRESS THAT HAS BEEN MADE, FEDERAL SUPPORT MUST BE CONTINUED AND IMPROVED UNTIL ECONOMIC PARITY IS ACHIEVED AMONG THE PEOPLES OF THIS NATION. A NECESSARY STEP TOWARD THIS GOAL IS EDUCATIONAL PARITY. INCREASED STUDENT

SUPPORT, INCREASED PROGRAM SUPPORT AND INCREASED OPERATIONAL SUPPORT ARE NECESSARY TO THE VIABILITY OF OUR COLLEGES AND UNIVERSITIES.

THE BEGINNING HAS BEEN SUCCESSFUL AND FOR THIS WE THANK YOU. THROUGH CONTINUED AND IMPROVED SUPPORT, THE FUTURE CAN BE JUST AS SUCCESSFUL.

GENTLEMEN, CONTINUE TO HELP US TO HELP YOU MAKE THIS GREAT NATION A BETTER NATION. MAY I CONCLUDE BY EXTENDING MY THANKS TO THE COMMITTEE AND TO CONGRESSMAN TRIBLE FOR PROVIDING ME THIS OPPORTUNITY.

STATEMENT OF DR. DAVID T. SHANNON

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE, LADIES AND GENTLEMEN: IT IS A PRIVILEGE FOR ME TO COME BEFORE YOU TODAY TO TALK WITH YOU ABOUT THE FUTURE OF OUR NATION'S HISTORICALLY BLACK COLLEGES. MY THREE COLLEAGUES HAVE ALREADY DESCRIBED FOR YOU SOME OF THE ISSUES.

I WANT TO HIGHLIGHT THREE CONCERNS.

FIRST, LET ME ADDRESS AN EDUCATIONAL ISSUE.

THERE ARE 100 COLLEGES AND UNIVERSITIES THAT HISTORICALLY HAVE MAINTAINED HEAVILY BLACK CONSTITUENCIES. MY OWN UNIVERSITY, VIRGINIA UNION, HAS BEEN IN OPERATION SINCE 1865 AND WE HAVE NEVER HAD MORE THAN A HANDFUL OF NON-BLACK STUDENTS. THE SAME HOLDS FOR MOST OF OUR SISTER INSTITUTIONS. WE ARE KNOWN AS "HISTORICALLY BLACK COLLEGES." BUT LET ME ASSURE YOU WE ARE NOT ALL ALIKE. HISTORICALLY BLACK COLLEGES ARE NO MORE A MONOLITH THAN HISTORICALLY WHITE SCHOOLS.

> MIT AND UCLA WERE NOT CUT FROM THE SAME CLOTH.
> NEITHER WERE VIRGINIA UNION AND MOREHOUSE,
> OR HOWARD AND TUSKEGEE.

THE HISTORICALLY BLACK COLLEGES ADD TO THE RICH DIVERSITY AVAILABLE TO AMERICAN STUDENTS. WE PROVIDE AN EDUCATIONAL OPPORTUNITY AND EXPERIENCE THAT BEST SUITS THE NEEDS OF MANY BLACK YOUNG PEOPLE. SOME BLACK STUDENTS THRIVE IN

PREDOMINANTLY WHITE SCHOOLS. OTHERS NEED AND EXCEL IN PREDOMINANTLY BLACK SCHOOLS.

OUR ACADEMIC EXPECTATIONS ARE JUST AS HIGH;

OUR DEMANDS ARE JUST AS STRINGENT, BUT MOST OF OUR STUDENTS NEED THE EXPERIENCE THEY GAIN AT HISTORICALLY BLACK COLLEGES. PHILOSOPHIES ABOUT RACIAL SETTINGS WILL DIFFER, BUT THE FACT REMAINS THAT THE VAST MAJORITY OF BLACKS WHO ARE SUCCESSFUL IN MAINSTREAM AMERICA OWE THEIR ALLEGIANCE TO A BLACK COLLEGE OR UNIVERSITY. THESE SCHOOLS ADD TO THE EDUCATIONAL FABRIC OF OUR NATION AND FILL A UNIQUE ROLE THAT NO OTHER INSTITUTION CAN OR WILL FILL. EDUCATIONALLY, THE COUNTRY NEEDS OUR SCHOOLS.

THE COUNTRY NEEDS OUR SCHOOLS, BUT OUR SCHOOLS STILL NEED THE COUNTRY. AND THAT BRINGS ME TO MY SECOND CONCERN, WHICH IS AN HISTORIC ONE.

EVERY COLLEGE WILL RECOUNT FOR YOU HOW IT WAS STARTED ON A SHOESTRING. IF YOU FOLLOW THAT METAPHOR, MOST OF OUR SCHOOLS STARTED BAREFOOTED. AND WE HAVE NOT YET ACHIEVED PATENT LEATHER LOAFERS. YET WE HAVE WALKED A LONG WAY. MANY OF US RECALL OUR MOTHERS LEARNING SEVEN WAYS TO COOK BEANS SO WE COULD HAVE VARIETY IN OUR DIET. SIMILARLY, MANY OF OUR COLLEGE ADMINISTRATORS HAVE HAD TO DEVELOP IMAGINATIVE WAYS OF STRETCHING OUR OTHER LIMITED RESOURCES. OFTEN WE HAVE TAUGHT WHEN TEACHERS NEVER EVEN CONSIDERED "FRINGE BENEFITS"; THEY WELCOMED MARGINAL SALARIES. THEY WERE NOT LESS QUALIFIED AS TEACHERS; THEY WERE NO LESS DEDICATED AS MENTORS. WE SIMPLY COULD RARELY PAY THEM WHAT THEY WERE WORTH. AT VIRGINIA UNION, WE USE THE PHRASE, ". . .IN PURSUIT OF EXCELLENCE." EXCELLENCE HAS ALWAYS BEEN AN AIM, BUT WE COULD RARELY CONCENTRATE ON EXCELLENCE. TOO MUCH OF OUR ENERGY WAS SPENT ON JUST SURVIVING. ENDOWMENT FUNDS AT MANY HISTORICALLY BLACK COLLEGES LOOK LIKE PETTY CASH FUNDS AT OTHER SCHOOLS. WE READ WITH ENVY WHEN OTHER SCHOOLS REPORT HOW MANY MILLIONS THEY HAVE IN RESERVE. AT OUR SCHOOL, WE HAVE BALANCED THE BUDGET THREE YEARS IN A ROW, AND WE HELD A CELEBRATION. NOW, AS OUR ALUMNI BEGIN TO ACHIEVE REWARDING POSITIONS IN SOCIETY, AS OUR BENEFACTORS EXPAND THEIR GENEROSITY, MANY OF OUR SCHOOLS ARE BEGINNING TO SEE THE PROSPECT OF BRIGHTER DAYS AHEAD. PROGRESS IS BEING MADE IN OUR SOCIETY ON MANY RACIAL FRONTS, BUT EACH STEP HAS A PRICE. THE NATION HAS TRIED TO OPEN ALL DOORS TO ALL PEOPLE, AND THAT IS GOOD. EVERY STUDENT CAN APPLY TO ANY SCHOOL. BUT SCHOOLS LIKE OURS MUST NOW WATCH WHILE STATES PLACE

BOUNTIES ON THE BEST BLACK STUDENTS AND THE BEST BLACK TEACHERS. IN THE NAME OF PROGRESS THEY CAN OFFER THEM ENTICEMENTS WE CANNOT MATCH BECAUSE WE DO NOT HAVE THE RESOURCES. WE ARE STILL GOING TO MAKE IT. WE ARE USED TO FINDING OBSTACLES IN OUR PATHS. WE TEACH STUDENTS TO CALL THEM STEPPINGSTONES.

HOW CAN OUR STUDENTS TURN OBSTACLES INTO STEPPINGSTONES?

THEY WILL NEED CONTINUED TUITION ASSISTANCE.
THEY WILL NEED MORE GUARANTEED LOANS.
THEY WILL NEED MORE COLLEGE WORK-STUDY.

OUR SCHOOLS HAVE CLIMBED A LONG HILL. THE CLIMB ISN'T QUITE AS STEEP AS IT WAS, BUT UNTIL WE CAN GET OUR MOMENTUM ESTABLISHED AND CAN GENERATE PRIVATE FUNDS ON AN EQUAL BASIS WITH OTHER SCHOOLS, PUBLIC SUPPORT IS STILL NECESSARY. WE NEED A TRULY FAIR SHARE OF THE PRIVATE FUNDING AND THE PUBLIC GRANTS AND ENTITLEMENTS THAT GO TO OTHER SCHOOLS.

HISTORICALLY BLACK COLLEGES ADD TO THE EDUCATIONAL DIVERSITY OF OUR COUNTRY AND ARE NEEDED FOR THAT REASON. THE SCHOOLS CONTINUE TO NEED ASSISTANCE BECAUSE WE HAVE NOT IN THE PAST HAD THE PRIVATE OR PUBLIC SUPPORT AVAILABLE TO OTHER SCHOOLS.

BUT I WANT TO MOVE ON NOW TO A SIMPLE ECONOMIC FACT THAT HAS AN IMPACT ON EVERY PERSON IN THIS ROOM. THE AVERAGE AGE OF THE WHITE POPULATION IS GROWING OLDER; THAT OF THE MINORITY POPULATION IS MUCH YOUNGER. THE RETIREMENT INCOME OF PEOPLE AT WORK TODAY MAY WELL DEPEND ON THE PRODUCTIVE EMPLOYMENT OF MINORITY YOUNG PEOPLE WHO ARE IN SCHOOL NOW. NOT JUST OUR RETIREMENT, BUT THE ECONOMIC VITALITY OF THE NATION WILL DEPEND UPON THE ECONOMIC, SOCIAL, AND CULTURAL HEALTH OF TODAY'S MINORITY YOUTH. FROM EXPERIENCE, WE KNOW THAT MANY OF THESE YOUNG PEOPLE WILL DEPEND UPON HISTORICALLY BLACK COLLEGES FOR THEIR PREPARATION. THE NATION CANNOT AFFORD TO SHACKLE THEM WITH LESS THAN QUALITY EDUCATIONAL OPPORTUNITIES.

FOR THESE REASONS, MR. CHAIRMAN, I URGE YOU AND THE MEMBERS OF THE APPROPRIATIONS COMMITTEE TO LOOK TOWARD YOUR SUPPORT OF STUDENTS IN HISTORICALLY BLACK COLLEGES WITH A COMPRHENSIVE VIEW. KNOW THAT THESE SCHOOLS ARE A NECESSARY AND VITAL PART OF THE AMERICAN EDUCATIONAL SCENE. RECALL WHAT WE HAVE BEEN ABLE TO ACCOMPLISH WITH VIRTUALLY NO RESOURCES AND IMAGINE THE CONTRIBUTION WE CAN MAKE TO THIS NATION WITH A LITTLE MORE TIME AND A LITTLE MORE MONEY. FINALLY, CONSIDER CAREFULLY THAT SUPPORT OF THESE COLLEGES COULD WELL BE THE

DIFFERENCE BETWEEN OUR NATION'S FUTURE ECONOMIC HEALTH AND ECONOMIC DIS-EASE.

MEMBERS OF THE COMMITTEE, I HAVE COME BEFORE YOU AS ONE OF THE SPOKESMEN FOR A PHENOMENAL GROUP OF INSTITUTIONS -- SCHOOLS THAT FOR THE MOST PART SHOULD HAVE, BY ALL LAWS OF ECONOMICS, HAD TO CLOSE YEARS AGO. BUT I AM PLEASED TO REPRESENT A CONSTITUENCY THAT IS AS COMMITTED TO THE REALIZATION OF THE AMERICAN DREAM AS ANY IN OUR LAND. WE HAVE DONE OUR BEST SO FAR. WE WILL CONTINUE TO DO IT, WITH YOUR HELP. THANK YOU.

STATEMENT OF WILBERT GREENFIELD

MR. CHAIRMAN AND MEMBERS OF THE SENATE APPROPRIATIONS COMMITTEE, I WAS PLEASED TO ACCEPT SENATOR TRIBLE'S INVITATION TO APPEAR ALONG WITH MY COLLEAGUES BEFORE THIS COMMITTEE FOR THE PURPOSE OF DISCUSSING THE FINANCIAL BURDENS BEING FACED BY THE HISTORICALLY BLACK COLLEGES AND UNIVERSITIES OF OUR COUNTRY - AND SPECIFICALLY VIRGINIA STATE UNIVERSITY.

TODAY, THESE INSTITUTIONS ARE FACED WITH REAL CONCERNS:

- NOT BEING ABLE TO INCREASE TUITION, ROOM, BOARD AND FEES DUE TO THE FACT THAT 80 - 90 PERCENT OF OUR STUDENT POPULATION COMES FROM FAMILIES WITH AN INCOME AT OR BELOW THE POVERTY LEVEL. OF THIS NUMBER, MANY ARE FROM SINGLE PARENT FAMILIES.
- THE PRESENT STATE OF THE ECONOMY YIELDING TO AN UNEMPLOYMENT RATE OF APPROXIMATELY 45-50 PERCENT OF YOUNG BLACKS AND APPROXIMATELY 20 PERCENT OF BLACKS IN GENERAL.

BE THIS AS IT MAY, THESE INSTITUTIONS MUST COMPETE WITH THE MORE AFFLUENT INSTITUTIONS FINANCIALLY FOR EXCELLENT FACULTY AND OFFER ATTRACTIVE SALARIES. THEY MUST COMPETE FOR THE HIGH POTENTIAL STUDENTS ACADEMICALLY WITHOUT THE NECESSARY SCHOLARSHIP FUNDS. THEY MUST MAINTAIN ADEQUATE FACILITIES AND A FUNCTIONAL PHYSICAL

PLANT WITHOUT A REDUCTION IN COST FOR SERVICES. THEY MUST PROVIDE FOR DEVELOPMENTAL STUDIES INORDER TO PRODUCE A MORE COMPETENT CITIZENRY EDUCATIONALLY. FOR THROUGH EDUCATION, MANY OF THE ILLS OF OUR COUNTRY CAN BE EFFECTIVELY AND EFFICIENTLY ADDRESSED. THROUGH THESE EFFORTS, A GREATER NUMBER OF OUR BLACK YOUTH WILL HAVE A CHANCE FOR THEIR MINDS TO BECOME ILLUMINATED.

THEREFORE, I STRONGLY PROPOSE AND SERIOUSLY URGE THIS COMMITTEE TO BECOME COMMITTED TO THE FOLLOWING:

1 INCREASE THE LEVEL OF THE PELL GRANT PROGRAM - ALLOWING MORE STUDENTS TO PARTICIPATE WITH AN INCREASED AMOUNT FOR THOSE MOST IN NEED.

2 PROVIDE INCREASED WORK-STUDY FUNDS TO THE HISTORICALLY AND PREDOMINATELY BLACK INSTITUTIONS.

3 MAINTAIN THE CAMPUS BASE PROGRAM - SUPPLEMENTAL EDUCATIONAL GRANTS.

4 INTRODUCE NEW LEGISLATION FOR ADDITIONAL FEDERAL AND STATE GRANTS.

5 LESS EMPHASIS ON LOANS THAT WILL BE DIFFICULT FOR LOW INCOME STUDENTS TO REPAY AND SUPPORT FAMILIES WHO ARE FAR BELOW THE POVERTY LEVEL.

WHILE I AM REQUESTING A REDUCTION IN LOANS TO SUPPORT THE COST OF EDUCATION OF STUDENTS ENROLLED IN HISTORICALLY BLACK INSTITUTIONS, I AM REQUESTING A SIGNIFICANT INCREASE IN THE COLLEGE WORK-STUDY APPROPRIATIONS. AN INCREASE IN COLLEGE WORK-STUDY APPROPRIATIONS WILL PERMIT THE FURTHER DEVELOPMENT OF INCREASED CAMPUS-BASED EMPLOYMENT AND OFF-CAMPUS EMPLOYMENT IN BOTH THE PUBLIC AND PRIVATE SECTORS. THIS EMPLOYMENT WILL PROVIDE STUDENTS WITH WORK ETHICS AND SKILLS WHICH WILL ENHANCE BOTH THEIR SUCCESS IN OBTAINING EMPLOYMENT AND ALSO THEIR RETENTION AND UPWARD MOBILITY IN THE

POSITIONS THEY OBTAIN. INCREASE THEIR PRODUCTIVITY THROUGH WORK-STUDY AND JOB PLACEMENT AND DEVELOPMENTAL PROGRAMS WILL ASSIST GREATLY THE COMMONWEALTH OF VIRGINIA, THE FEDERAL GOVENMENT, AND PRIVATE AGENCIES IN ACHIEVING THEIR AFFIRMATIVE ACTION COMMITMENTS. PUBLIC AND PRIVATE AGENCIES HAVE OFFERED TO EMPLOY APPROXIMATELY FOUR TIMES MORE CWS STUDENTS THAN THERE ARE FUNDS AVAILABLE AT VIRGINIA STATE UNIVERSITY (VSU).

SHOULD YOU HAVE RESERVATIONS RELATIVE TO THE SIGNIFICANCE OF INCREASED COLLEGE WORK-STUDY FUNDS, I REQUEST THAT CWS FUNDS FOR VSU BE INCREASED BY 50% FOR THE NEXT TWO YEARS. VSU WILL REPORT ON THIS INITIATIVE AND THE RESULTS MIGHT PROVIDE USEFUL INFORMATION RELATIVE TO THE FEASIBILITY AND JUSTIFICATION OF INCREASING SUCH FUNDS AT OTHER HISTORICALLY BLACK INSTITUTIONS.

AT VSU THE MEDIAN FAMILY INCOME OF OUR STUDENTS THIS YEAR IS $11,747.20. THIS MEANS THAT 2110 FAMILIES HAD AN INCOME OF $11,747.20 OR LESS. 31 PERCENT OF OUR STUDENTS COME FROM FAMILIES WITH AN INCOME OF 6,000 OR LESS.

THE MEDIAN FAMILY INCOME FOR OUR COUNTRY WAS $21,023. FOR THE STATE OF VIRGINIA, IT WAS $26,153.

I RECOMMEND SUPPORT OF THESE INSTITUTIONS THAT ARE CONTINUING TO PRODUCE THE MAJORITY OF THE BLACK LEADER AND BLACK GRADUATES OF OUR COUNTRY.

Senator TRIBLE. Mr. Chairman, I thank you for your warm welcome and for your generous allotment of time. We will not exceed the time that you have given us this morning.

I am in distinguished company this morning and would like to introduce, for the sake of the record, Dr. Harrison Wilson, the president of Norfolk State University; Dr. Wilbert Greenfield, the president of Virginia State University; and Dr. Oscar Prater, who is the vice president of administration at Hampton Institute.

Mr. Chairman, a few words of introduction if I may. As you well know, the diversity of our colleges and universities has contributed markedly to America's economic, educational, and cultural well-being.

One significant element in this rich cultural fabric is in jeopardy. America's historically black colleges and universities are threatened by rising costs and declining enrollments.

These institutions have produced generations of leaders, fostered a sense of identity and community, and met the needs of the economically disadvantaged. We must ensure the continued vitality of these important educational institutions.

In Virginia, we are blessed with a number of these very fine schools. Today you have represented on this panel the leaders of Norfolk State University, Virginia Union University, Virginia State University and Hampton Institute.

All of these schools offer exemplary educational opportunities and they must continue to do so. Congress and the administration have responded positively to this critical situation.

Last year the funding for aid for historically black colleges was increased and it's my hope that again this year adequate funding will be made available for this important purpose. To that end, I thought it would be important for the record and for the deliberations of this important subcommmttee to hear from these distinguished gentlemen who are in the trenches, who each day are providing educational opportunities to young Americans.

So I will yield to the experts, Senator Rudman, and perhaps, as I often do, I'll go to my right first and yield to Dr. Harrison Wilson and ask him to share his thoughts and concerns; and then we'll move to the left.

Senator RUDMAN. Let me ask you just one question before the witnesses start testifying, which might be helpful to me because—I'm familiar with the institutions, but unfamiliar with how they are funded.

Now, Norfolk State University, Virginia State University, are they both part of the State university system of the State of Virginia?

Senator TRIBLE. Yes; you have here a mix of public and private schools.

Senator RUDMAN. And Hampton Institute and Virginia Union are private institutions which are not affiliated with the State university system of the State of Virginia.

Senator TRIBLE. That is correct, sir.

Senator RUDMAN. Fine. Thank you very much.

Senator TRIBLE. That is correct. Harrison?

Dr. WILSON. Thank you, Mr. Chairman, Senator Trible. First of all I want to thank you, Senator, for providing us this opportunity and we've appreciated the support and help and assistance that you have always given us. We appreciate it and support you, and we just feel fortunate to have a Senator such as you representing us.

Senator TRIBLE. Thank you, sir.

Dr. WILSON. Let me just take 1 minute. Since you're not really familiar with our schools per se, our school is a State institution. It has 7,500 students, 85 percent of which have a family income of $10,000 or less. So it's an institution that I call an institution similar to the kinds of students that went to many of our institutions 50, 60 years ago in this country.

Most of our students are first generation college students, the first ones of their family to go to college. So it's a human resource as I see it.

We happen to have in Virginia the largest ROTC Program. We have that as part of our mission. We feel that that's very important and I'm saying that to say that not only are we important to the Commonwealth, but we're important to the country, the Nation in just that one factor alone.

I know, Senator, that you realize that about 40 some percent of the minority youth are unemployed in this country and this includes the young people who want to go to college. They have the potential. They want the opportunity; and, of course this is the land of opportunity. I think it's very important that they have this chance.

So, No. 1 on our list, I would say, would be the financial aid. Not so much the loans, because it's hard for our students whose parents do not have a history of having bank accounts and bank connections to get loans. So it's the real grant kind of money that we need.

I want to hasten to say that our students aren't just there on financial assistance. I would say at least 75 percent of our students work and go to school. They do have financial assistance, but they have to work in order to maintain themselves.

We also have an older student at our institution. We are an urban institution. We have many people who come back to go to college after starting a career or maybe they didn't have an opportunity to go to college when they finished high school and later on they realized this is what they want to do.

So our average age student is about 26, 27 years old. So the financial assistance is very significant.

We feel that with that type of assistance, you get a person who is really going to be a taxpayer and a value to the community and the country. So that's our first area.

The second is the title III program. The title III program has been good to the predominently black institutions over the years. In private schools as well as State institutions, it's important for the enrichment of the universities.

Now, that's going to change, as I understand it, to where a school that can raise a certain percentage of money can have that matched by the Federal Government. We're ready and acceptable to that challenge.

But it still isn't the same thing as having money that you can hire people and that you can have types of programs that enrich your universities.

One of the programs we have is remedial education. I heard the Director of the NIH say in California recently that it's important that the remedial and competency kinds of programs continue in this country.

There are those who say they shouldn't. Now, I would say it's a touch of elitism if we do not do this. This isn't just minorities. This is something because they are not getting it in the elementary and secondary schools.

I'm of the opinion we cannot afford to let a generation of students miss college because of a lack of preparation. I'm all for higher standards of preparation and all that; but I'm talking about the students that are presently in the system getting into the college system.

Senator RUDMAN. What you're saying essentially is a lot of these youngsters have great potential. For whatever reasons, in their secondary schools they just have not had the education that they really needed, but if you can get a hold of them and apply this remedial program you can bring them up to speed fast enough to have them get the proper benefit of your educational institution.

Dr. WILSON. Right. And we've done this over the years, Senator. It isn't anything that we're just starting. It's something that we've done and been able to do very successfully; and you have to want to do this.

In other words, the school has to have this as part of their mission to take these students from where they are and bring them up to where they should be, and then take off from there. I don't want to go into percentages of people that we have throughout the country that came through these particular programs.

So title III is very important to us, but the final area are the grants, the research grants. We're able to do many of the things that are published, but for some reason the communication system is off and we find out late that there are grants possible and that the timeframe for applying for these grants is usually short.

Without a lot of expertise, it takes more time to do this. So we need to know up front when there are possible research grants that we can handle, that we can make a real contribution to our society.

I want to thank you for this opportunity. Those are the areas that I would like to discuss.

Senator RUDMAN. Well, thank you very much. I'm very interested in institutions such as yours and particularly because of the obvious need over the next 20 years in this country with the changing mix of our population to assure that young people who come from institutions such as yours do have the opportunity.

Let me ask you just a couple of questions. We are going to be considering this bill and it's helpful to have some information.

You have about 7,500 students.

Dr. WILSON. Yes.

Senator RUDMAN. You have graduate programs as well.

Dr. WILSON. Yes; we do.

Senator RUDMAN. What graduate schools do you have within the institution?

Dr. WILSON. We have school of social work, school of MBA program; we have a program in communications; we also have one in mass communications, television, and so forth.

Senator RUDMAN. Now, do the young people in those graduate programs have generally less of a problem, same problem, or more of a problem in getting funding for that kind of education?

Dr. WILSON. Well, they have more of a problem.

Senator RUDMAN. More of a problem.

Dr. WILSON. If you're in an urban setting, you have a little better opportunity because those students work. For instance, in mass communications many of the television engineers, people behind the scenes, as well as in front of the camera are students. The same way with the radio programs and so forth. So they work and go to school.

I don't have any problem with that. I like the work orientation. But I did want to go back and say this about the remediation, Senator; that if we hadn't had the World War II GI bill many of the fellows that came into the colleges for the first time without the GI bill, without the opportunity wouldn't be where they are today.

Many of our students are like many of those fellows that suddenly saw that they could go to college. I think you would admit that that has been one of the best programs we've ever had in this country.

Senator RUDMAN. How many of your students actually live on the campus?

Dr. WILSON. We have 2,000 of the students.

Senator RUDMAN. And the others?

Dr. WILSON. Others either live in homes or they rent apartments; and then the others commute.

Senator RUDMAN. And what do you estimate to be the cost for a youngster in the undergraduate school to go through your institution?

Dr. WILSON. About $4,000. Ours is one of the cheapest in terms of costs in the State. We try to keep it down to where we don't price ourself out of business.

Senator TRIBLE. Mr. Chairman, if I might just interrupt a minute.

Senator RUDMAN. Yes.

Senator TRIBLE. We have been joined by Dr. David Shannon, who is the president of Virginia Union University and one of our very fine private colleges in Virginia. So now our panel is intact.

Senator RUDMAN. Well, thank you very much. I might have another question or two, but it's good to get the record as complete as we can.

One last question. Of those $4,000 or so—well, of the entire student body, I assume you get a very high percentage of young people who are getting one form of financial aid or another.

Dr. WILSON. Yes, sir; about 85 percent are getting some kind, State financial aid. By the way, the State of Virginia has improved and has continued to support the financial aid project. So their State funds have grown.

But the escalating costs—see, we're moving from, say, $2,000, $2,500 to $4,000 in about 6 years and that's quite a bit of money.

Senator RUDMAN. All right.

Senator TRIBLE. Good. Dr. Greenfield.

Dr. GREENFIELD. Thank you, Senator Rudman and members of the Senate Appropriations Committee. I was pleased to accept Senator Trible's invitation to appear along with my colleagues before this committee for the purpose of discussing the financial burdens being faced by the historically and predominantly black colleges and universities of our country, specifically Virginia State University.

Virginia State University celebrated its 102d year this past March and it's one of the 1890 land grant institutions in the country. We have approximately 4,500 students with programs in about 60 different areas, graduate programs in about 24 different areas.

Today, these institutions are faced with real concerns. One, not being able to increase tuition, room and board, and fees due to the fact that 80 to 90 percent of our student population comes from families with an income at or below the poverty level. Of this number, many are from single-parent families.

The present state of the economy yields to an unemployment rate of approximately 45 to 50 percent of young blacks and approximately 20 percent of blacks in general. Now, I just might be repeating some of the things that my colleagues have said or will be saying, but nevertheless I think it's important for us to repeat these.

Be this as it may, these institutions must compete with the more affluent institutions financially, for excellent faculty, and offer attractive salaries. They must compete for the high potential students academically without the necessary scholarship funds. They must maintain adequate facilities and a functional physical plant without a reduction in costs for services.

They must provide for developmental studies in order to produce a more competent citizenry educationally for through education many of the ills of our country can be effectively and efficiently addressed. Through these efforts, a greater number of our black youth will have a chance for their minds to become illuminated.

Therefore, I strongly propose and seriously urge this committee to become committed to the following: To increase the level of the Pell Grant Program allowing more students to participate with an increased amount for those most in need; provide increased work/study funds to the historically and predominantly black institutions; maintain the campus-based programs, that would be the supplemental educational programs; introduce new legislation for additional Federal and State grants; make less emphasis on loans that would be difficult for low-income students to pay; and support families who are far below the poverty level from the beginning.

While requesting a reduction in loans to support the cost of education of students enrolled in historically black institutions, I am requesting a significant increase in the college work/study appropriations. An increase in college work/study appropriations will permit the further development of increased campus-based employment and off-campus employment in both the public and private sectors.

This employment will provide students with work ethics and skills which will enhance both their success in obtaining employment and also their retention and upward mobility in a position they obtain, increase their productivity through work/study and job placement, and the development of these programs will assist greatly the Commonwealth of Virginia, the Federal Government, and private agencies in achieving their affirmative action commitment.

Public and private agencies have offered to employ approximately four times more college work/study students than there are funds available at Virginia State University; and I can speak specifically for Virginia State. Should you have reservations relative to the significance of increased college work/study funds, it would be wonderful to have an experimental project whereby these funds could be increased tremendously over 1 year to see the results and to see the upward mobility in industry.

At Virginia State University the median family income of our students this year is $11,747.20. This means that of the 4,500 students 2,010 families had an income of $11,747.20 or less.

Thirty-one percent of our students come from families with an income of $6,000 or less. The median family income for our country was $21,023 this past year. For the State of Virginia, it was $26,153.

I recommend support of these institutions that are continuing to produce the majority of the black leaders and black graduates of our country; and this could also be accomplished additionally through title III and through each agency of the Federal Government really adhering to the White House initiatives.

I think those initiatives are great initiatives. If each agency would place emphasis on and put those initiatives on the proper perspective I certainly think that this would be of tremendous value to our institutions. Thank you.

Senator RUDMAN. Thank you very much. Your income statistics state a very powerful case.

Let me ask you just a couple of questions about your institution, Doctor.

Dr. GREENFIELD. Yes, sir.

Senator RUDMAN. What is the enrollment of your institution?

Dr. GREENFIELD. We have about 4,500 students. We are located in Petersburg at a little town called Ettrick. That's in sort of a rural area and we are one of the 1890 land grant institutions.

Senator RUDMAN. What is the tuition? Or what is the cost of attending your institution?

Dr. GREENFIELD. $4,200 for an in-State student and about $5,200 for an out-of-State student.

Senator RUDMAN. And what kind of support do you get from the State system?

Dr. GREENFIELD. We do get some State funds. As my colleague has indicated, we do get some State grant funds for our students from the State of Virginia. There is also some aid for some students from other States.

Our students come from approximately 38 different States and 26 foreign countries. We operate one of the most successful projects through the USAID program in the country of Kenya in the history of that program; and we are very proud of that.

Senator RUDMAN. Well, as part of the State university system, it varies from place to place but does the State Legislature, the Assembly in Virginia, appropriate a fairly substantial amount of money for you each year?

Dr. GREENFIELD. Senator, I'd like to say that we are not State supported but State assisted at this particular point.

Senator RUDMAN. I see.

Dr. GREENFIELD. Roughly 37——

Senator RUDMAN. That's a very fine distinction, but I think I understand it. [Laughter.]

Dr. GREENFIELD. I'll have to define that. I have to write the definition.

Senator TRIBLE. The chairman can appreciate that.

Senator RUDMAN. I understand that.

Dr. GREENFIELD. We receive approximately 62 percent of our funds, I think, from State funds and the rest must come from tuition fees.

Senator RUDMAN. What is your annual operating budget?

Dr. GREENFIELD. The annual operating budget, including all grants, is about $40, $42 million a year. That includes the Federal grants and all funds from all sources.

Senator RUDMAN. Right. Thank you very much.

Senator TRIBLE. Mr. Chairman, why don't we, now, turn to the private sector——

Senator RUDMAN. All right.

Senator TRIBLE [continuing]. To two very fine private colleges in Virginia. Perhaps we should turn to Dr. Shannon first who is president of Virginia Union University.

Senator RUDMAN. Good morning, Dr. Shannon. Where is Virginia Union University located?

Dr. SHANNON. In Richmond, VA.

Senator RUDMAN. In Richmond. All right.

Dr. SHANNON. From a statistical point of view, we were founded in 1865. We are a university having an undergraduate school basically focusing on liberal arts and then we have a graduate school of theology.

One of our earlier schools was founded here in Washington, DC, the Whalen Academy, in the 19th Street Baptist Church. We are very proud of that Washington connection. Then, in Richmond, we have the Richmond Theological Center.

In 1899 these two were combined with the Woman's College, which was the Hawks Horne Memorial College, and then it became Virginia Union University.

It is a privilege for me to come before you today to talk with you about the future of our Nation's historically black colleges. My three colleagues have already described for you some of the issues and I want to highlight three concerns.

First, let me address an educational issue. There are approximately 103 colleges and universities that historically have maintained heavily black constituencies.

Our own university, Virginia Union, has been in operation since 1865 and we have never had more than a handful of nonblack students. The same holds for most of our sister institutions.

We're known as historically black colleges; but let me assure you that we are not all alike. Some are State and some are private. Historically black colleges are no more a monolith than historically white schools.

MIT and UCLA were not cut from the same cloth; neither were Virginia Union, Moorehouse or Howard, and Tuskegee.

Historically black colleges add to the rich diversity available to American students. We provide an educational opportunity and experience that best suits the needs of many black young people.

Some black students thrive in predominantly white schools. Others need and excel in predominantly black schools. Our academic expectations are just as high. Our demands as just as stringent.

But most of our students need the experience they gain in historically black colleges. Philosophies about racial settings will differ, but the fact remains that the vast majority of blacks who are successful in mainstream America owe their allegiance to a black college or university.

These schools add to the educational fabric of our region and fill a unique role that no other institution can or will fill. Educationally, the country needs our schools.

The country needs our schools, but the schools still need the country. And that brings me to my second concern, which is an historic one.

Every college will recount for you how it was started on a shoestring. If you follow that metaphor, most of our schools started barefooted. And we have not yet reached patent leather loafers. Yet we have walked a long way. Many of us recall our mothers learning seven ways to cook beans, so we could have a variety in our diet. Similarly, many of our college administrators have had to develop imaginative ways of stretching our other limited resources. Often we have taught when teachers never even considered fringe benefits; they welcomed marginal salaries. They were not less qualified as teachers; they were no less dedicated as mentors. We simply could rarely pay them what they were worth.

At Virginia Union, we use the phrase, "in pursuit of excellence." Excellence has always been our aim, but we could rarely concentrate on excellence. Too much of our energy was spent on just surviving. Endowment funds at many historically black colleges look like petty cash funds at other institutions. We read with envy when other schools report how many millions they have in reserve. At our school, Virginia Union, we have balanced the budget 3 years in a row, and we held a celebration.

Now as our alumni begin to achieve rewarding positions in society, as our benefactors expand their generosity, many of our schools are beginning to see the prospect of brighter days. Progress is being made in our society on many racial fronts, but each step has a price. The Nation has tried to open all doors to all people, and that is good. Every student can apply to any school, but schools like ours must now watch while States place bounties on the best black students and the best black teachers. In the name of progress they can offer them enticements we cannot match, because we do not have the resources. We are still going to make it. We are used to finding obstacles in our paths. We teach students to call them stepping stones.

How can our students turn obstacles into stepping stones?

One, they will need continued tuition assistance. My colleagues have already made mention of that.

Also, they will need more guaranteed loans.

And third, they will need more college work/study.

Our schools have climbed a long way. The climb isn't quite as steep as it was, but until we can get our momentum established and can generate private funds on an equal basis with other schools, public support is still necessary. We need a truly fair share of the private funding and the public grants and entitlements that go to other schools.

Historically, black colleges add to the educational diversity of our country and are needed for that reason. The schools continue to need assistance because we have not in the past had the private or public support available to other schools.

But I want to move on to a simple economic fact that has an impact on every person in this room. The average age of the white population is growing older; that of the minority population is much younger. The retirement income of people at work today may well depend on the productive employment of minority young people who are in school now. Not just our retirement, but the economic vitality of this Nation will depend upon economic, social, and cultural health of today's minority youth. From experience, we know that many of these young people will depend upon historically black colleges for their preparation. The Nation cannot afford to shackle them with less than quality educational opportunities.

For these reasons, Mr. Chairman and committee members, I urge you to look toward your support of students in historically black colleges with a comprehensive view. Know that these schools are a necessary and vital part of the American educational scene. Recall what we have been able to accomplish with virtually no resources and imagine the contribution we can make to this Nation with a little more time and a little more money. Finally, consider carefully that support of these colleges could well be the difference between our Nation's future economic health and economic disease.

Members of this committee, I come before you as one of the spokespersons for a phenomenal group of institutions—schools that for the most part should have, by all laws of economics, had to close years ago. But I am pleased to represent a constituency that is as committed to the realization of the American dream as any in our land. We have done our best so far. We will continue to do it, with your help. Thank you.

Senator RUDMAN. Thank you very much, Dr. Shannon. I think your statistics, in terms of the age of the population, are very interesting and something that is well known to many of us who are interested in things of this sort and make a strong case for your constituency, because without the kind of educational opportunities that you offer, you wind up with a very unskilled and uneducated population. So you do make a good point.

Let me ask you the same questions that I asked your colleagues.

What is the enrollment of your institution?

Dr. SHANNON. We have 1,200 students in undergraduate and 133 students in our graduate school of theology.

Senator RUDMAN. What would be the average annual cost of—all costs of your students?

Dr. SHANNON. For the undergraduates, it will be around $6,000 a year, and for the graduate school, because it is a graduate school of theology, it is cheaper. It is $4,000 a year.

Senator RUDMAN. And the median incomes of the families of these young people is probably similar—comparable to what your college fees are?

Dr. SHANNON. Yes.

Senator RUDMAN. What is your operating budget?

Dr. SHANNON. About $10 million.

Senator RUDMAN. And of that, what percentage has been from outside assistance of various kinds?

Dr. SHANNON. Well, by being a private school, we get most of our money—we get about 37 percent of our funds from tuition fees. We get about another 15 percent from our endowment, and then we get about 20 percent from churches. And the rest of it we get from gifts and grants. We have very few dollars we get directly from the Federal Government. And the only money that we get from the State is through what is called a TAG or tuition assistance grant. This is about $915 that each Virginia student gets who goes to a private school. Most of our money comes through the gifts and grants of alumni, corporations, and the churches.

Senator RUDMAN. Thank you very much, Dr. Shannon, very interesting.

Senator TRIBLE. Finally, Mr. Chairman, we'll hear from Dr. Oscar Prater, who is the vice president of administration for Hampton Institute, a very fine school. It stands at the mouth, Mr. Chairman, of Hampton Roads, overlooking the Chesapeake Bay and the James River.

Dr. PRATER. Thank you, Mr. Chairman, Senator Trible. Mr. President, Mr. William Harvey is unable to attend and he asked me to represent him.

Black colleges have primarily served black students. The student population served in the past, presently being served and who will be served in the future acts as the driving financial force through which black colleges are primarily supported. To assess the financial barriers facing black colleges, then is to assist economic status of the above student groups. For it is their ability to pay tuition fees at the level needed, their ability to support these colleges financially through alumni contributions at the level needed and their ability to obtain positions of influence with private and governmental sources in sufficient quantities to determine the financial conditions that these institutions must face.

I shall not repeat the statistics on this economic group at this time.

Historically, black institutions have been able to reach their present success through programs so far in person—for the personal out point. Since its inception at Hampton Institute, the title III Aid Program has impacted every segment of the college: The academic programs, student services, faculty and staff development, administrative and management function, we have developed and fully implemented a long-range planning process and institutional research program that provides a sound basis for policy development, decisionmaking, and contingency planning.

We are instituting a collegewide management information system that will strengthen our ability to effectively manage and operate the administrative, academic, and support areas which make up the total institution.

We have improved the college's fundraising capacity through staff development, public relations programming, alumni involvement, and personal leadership through the administration of the college. We have developed new academic programs in response to the changing needs of our constituents and have strengthened existing programs to maintain the relevance to current educational requirements.

We have provided faculty opportunities to retool, retrain or to improve their ability to teach.

In general, students have been assisted in their adjustment to college through academic and personal counseling programs conducted by a staff that has been trained to provide appropriate and effective student service programs. It has been due to the support of the Federal Government through gifts and grants that these very positive strides have been made of our traditional sources of revenue. Students are being asked to contribute an increasingly larger percentage of the cost of their education. Given their economic background, the financial burden works to deny these students an equal opportunity to pursue higher education.

Thus Hampton Institute and other black colleges and universities will need the continued and improved support of the Federal Government.

These institutions do not have the resources required to routinely advance their programs, facilities, and physical plants, in keeping with the rapid changes being made in our society.

Technology is vital to the continued growth of this country, yet this cost is inordinately high and in most instances prohibitive for minority institutions.

And I am sure that you have heard these facts numerous times. I must say, however, the black colleges are a valuable resource to this Nation, one that the country can ill afford to lose.

To continue the progress that has been made, Federal support must be continued and improved, until economic parity is achieved among the peoples of this Nation. A necessary step toward this goal is educational parity. Increased student support, increased program support, and increased operational support are necessary to the viability of our colleges and universities.

The beginning has been a successful one, and for this we thank you. Through continued and improved support, the future can be just as successful.

We ask that you continue to help us to help you to make a great nation a better nation.

May I conclude by extending my thanks to Senator Trible and the committee for providing me with this opportunity.

Senator RUDMAN. Thank you.

I am now joined by my colleague, Senator Inouye of Hawaii.

I want to just ask several questions about your institution. What is the enrollment of Hampton?

Dr. PRATER. We have 4,300.

Senator RUDMAN. What is the mix of the curriculum?

Dr. PRATER. We are comprehensive. We have professional programs as well as liberal arts.

Senator RUDMAN. What is the average cost?

Dr. PRATER. $5,300.

Senator RUDMAN. And I assume a very heavy portion of that comes from outside sources, outside of tuition?

Dr. PRATER. We have a $26 million budget, $8 million through tuitions and gifts, grants, and other sources.

Senator RUDMAN. Let me ask this question of all of our witnesses, other than Dr. Shannon, although Dr. Shannon can answer, although, I don't think it applies to your institution. Do you have in your institution some reasonably technical curricula in engineering, mathematics, computer sciences, and so forth?

Dr. WILSON. We have majors in mathematics, engineering, electronics. We also have a dual degree in engineering with Old Dominion University. In other words, the State does not duplicate. And I think this is a very positive aspect of our program in cost savings. So we do have technical programs. And not only that, but the vocational educational programs, and many of our students work in the various industries, as well as that.

Senator Rudman. The same with the rest of you?

[All witnesses said yes.]

Senator Rudman. Now, as I understand it—I would start off by telling you, just as a matter of interest, that I founded a college in New Hampshire called Daniel Webster College, founded 25 years ago, and it's now about the size of Dr. Shannon's institution. Highly technical in nature. It shares with students of every rank and nature. So the stories that I'm hearing from you today are not dissimilar to the struggle of that institution which struggles with very little endowment and low tuition. But in trying to institute programs to meet today's needs in the job market, because obviously, you want your young people to have employment, do you find that the curricula which I've just asked you about are very, very expensive to put in place, the computer sciences, the technology programs, and so forth?

Dr. Greenfield. I think it is very, very expensive today. In the high technology area, there is very much increased demand. And one area that I want to speak of that my colleague didn't. In my institution, we're concerned with agriculture, in addition to the other departments, and we made up our mind that we're going to concentrate on the small farmer and develop the expertise to deal with the small farm, because the population of the world today, many of them will be living on small acreage.

Senator Rudman. I asked the question, because it seems to me that a number of years ago, there were some Federal programs that gave stronger assistance in the acquisition of laboratory equipment and engineering equipment, and so forth. And those programs do not exist today; am I correct?

[All witnesses said yes.]

Dr. Wilson. One of the problems is, they gave this equipment—it went to the "haves." It went to the big engineering schools throughout the country. And the problem is that "bigger isn't better," as we all know.

And the other thing that we find is that we find some very talented students who are economically deprived. In other words, there isn't a correlation between having money and having intelligence. And so for that reason, too, we find that so often, we miss the boat in not giving opportunities to people. And thank goodness, in Virginia, we have very fine support, I feel, from the State. And they have pushed us—we're an urban school, so they have pushed into this area of technology. And we have always had the vocational programs, but we do need the grant from the Federal Government to keep this going.

One other thing I wanted to say, Senators, and it's a fact of life. With the high percentage of unemployed teenagers, we know there's a high correlation between that and crime. And we know that the growing institutions for our country, our—our criminal institutions, and that cost ranges anywhere from $15,000 to $30,000 to $35,000 a year. And you get very little return.

And my feeling is, and I've said this many, many times.

If you have a teenager who wants an opportunity and he can't get it, and in return you have a debt of $15,000 to $20,000, you have to take a—you have to look at this in perspective.

Senator RUDMAN. I think all the time that I served as attorney general, we had certain problem youngsters that couldn't be handled within the State correctional system for young people and were being put in special institutions, costing the taxpayers of New Hampshire $18,000 a year, and we had a great many of them. And you make a strong case.

I think probably the most significant parts of your testimony here this morning tend to be, as well as human, (*a*) the median income of your students in the institution, (*b*) the population mix and the age of that population. And (*c*) to acknowledge the disaster we have in employment, not only of young black people, but of black people entering society. And I think you will find the chairman of this subcommittee, Senator Weicker, and the chairman of the full committee, Senator Hatfield, are most understanding of that problem, and I would hope that we would have some results.

And I think your testimony this morning is most important, because although many Senators have other things to do this morning and are not here, I can assure you that their staffs are here and they will hear about your testimony.

Dr. GREENFIELD. I'd like to make one final comment, Senator. This has been alluded to before, but I'd like to bring it home again. I think it should be known worldwide that through these institutions, we have the expertise and experience in dealing with the caliber of students that we are talking about. This is not a new thing to us. We need assistance and help to continue these efforts, so that we can produce more productive citizens for our society.

Dr. WILSON. One last point, too, Senator. We feel that we have graduates from many of the Third World countries that are leaders in those countries. We have good contacts with these alumni and they are not used as they should be, in our opinion, and it can be a great help, we think, to have this kind of one-on-one, when there is time to have a trip to Kenya or to have a trip to some of the other foreign countries, where we have graduates in key governmental bodies.

Senator RUDMAN. I think that's a very important point that's lost on most people.

Dr. WILSON. They can use those. We want to be used. We want to be of use to our country, as well as providing assistance.

Senator RUDMAN. Senator Inouye, would you like to ask any questions?

Senator Inouye. I am sorry I wasn't here at the beginning, but from what I've heard, I think it would be moneys well spent.

Senator TRIBLE. Thank you for your support, gentlemen.

Senator RUDMAN. Thank you very much for bringing this testimony before the committee. I hear a lot of testimony. Yours has been very, very interesting. I think very valid, and in an evidentiary way, certainly gives this committee some strong support for what most of us would like to do.

Thank you very much.

Senator TRIBLE. Thank you very much.

Senator RUDMAN. We'll now turn the chair over to Senator Inouye, who will help me call the next witness.

STATEMENT OF HON. VIC FAZIO, U.S. REPRESENTATIVE FROM CALIFORNIA

Senator INOUYE [presiding]. Our next witness is the distinguished Congressman from the State of California, the Honorable Vic Fazio.

Mr. FAZIO. Thank you, Senator.

Senator INOUYE. I have had the opportunity to read your testimony, and after reading it, felt that I should be over there with you testifying.

Mr. FAZIO. Well, I must say I was pleased to see you take the chair. I think we are very simpatico on this issue.

Senator INOUYE. Well, the problems you have are absolutely similar to ours. California and Hawaii, because of climatic conditions and ethnic diversity, are very attractive to those from the Pacific area.

Mr. FAZIO. Well, I certainly come at this from a very positive perspective. Three of my grandparents were not born in this country, and I am a real believer in the benefits that immigration brings to our society both in terms of creativity and initiative, enrichment of our cultural backgrounds.

I think the real success story in California and throughout the country are those people, particularly from Indochina, who have joined us in the last 5 years. It is something that will be another chapter in the rich heritage of immigration in our country's history.

But we do have some problems, and the problems are financial. I think if we were to sight any negative reaction during the depths of the recession from my constituents and others in California who have been there of longer duration, it relates specifically to the impact on social services, the educational system, and other public services that are brought about by the schedule of immigration.

California at this point has experienced in the last 5 years a 100-percent increase in the number of Indochinese that have joined us, a third of those that have settled elsewhere have decided to move on to California to join a very large contingent of people who came there originally.

So we have a very severe problem. Some of these people, of course, have been able to find jobs very quickly and have integrated into the fabric of our State. Others that come from the mountain areas, where their educational background even in their homeland was rather limited and have had a rather hard time making the adjustments.

So obviously it has cost our State a great deal of money, and during this period when we have had this 100-percent increase in the number of people who have joined us, there has been an absolute reduction of 25 percent in the amount of money that was available in 1981 from the Federal Government.

When you come to this committee—and I will be visiting Mr. Natcher in the House for a very specific reason, and that is that we are suffering this year from an even more dramatic reduction in the assistance that we have been led to expect—not only do we have a reduction in the social service funding area, we have also had a transfer of funds from the Targeted Areas Program which was aimed directly at those regions of the country, those counties and cities that had a very large influx of these people.

So we are here on two fronts. We frankly think we have an issue on policy because it is a humanitarian purpose, and we have a strong bipartisan sense from the Congress that we bring these people here and help integrate them into our society.

But, also, as members of the Appropriations Committee, as you and I are, we have a real interest in what we think may be a case of impoundment and certainly a confrontation with the figures that we reached in the continuing resolution of last year.

We are continuing to do some research. Our delegation is to see if the Comptroller General agrees with our definition of the problem. We are also, of course, going to be lobbying the White House and HHS to remonstrate with OMB over the reductions that have been visited upon us.

But I hope we can make a case to the appropriate committees that California certainly needs a full-funded appropriation to take care of these burdens that I think everyone understands we must meet, and I think it is clearly contrary to the national purpose, the national goal to leave the burdens to the State, in this case a State that has more refugees than the next nine put together, and that is really an unfair transfer of Federal responsibility.

Senator INOUYE. I agree with you completely. I have always maintained that the refugee problem is a problem resulting from our national policy. I wasn't aware that it was as high as 46 percent in the last 9 years.

Mr. FAZIO. We haven't been able to document in a timely way all the transfers that people make once they initially locate here back to California, where the environment, the cultural affiliations have really attracted them.

It is understandable that they would feel more comfortable with people that speak their language, with people who share their ethnic traditions, where they can buy food and other services that are related to their backgrounds.

It is something, I think, that California is pleased to provide as a home, a refuge for these people. At the same time we have the additional burdens, and there is occasionally some backlash to State and local taxes, and we must provide for this purpose.

The stories are legion, but what we describe as overcrowded schools where people go to learn our language in the evening, there is no question that this is not a group of people who want to separate themselves off. They don't want to do this. They want to become full, active, employed participants in our society.

But we have got to have the wherewithal to help them without burdening other people in our society, currently and just recently—who currently are just struggling through very high rates of inflation and high rates of taxation which people can't accommodate.

Senator INOUYE. I can assure you, as one member of this committee, I will do my best, and I believe I can speak for the chairman, also, who is very supportive of this.

We have one problem, as you know, and this matter has not been authorized, but whenever we can we will see that your burden is not disproportionately large to others.

Mr. FAZIO. We thank you. We thank you very much, Senator.

I know Senator Wilson and Senator Cranston have together been in touch, and I know this is a bipartisan issue by the House delegation, and so I hope with that kind of backing we can make some progress this year on what is evidently a very, very difficult budget year for all of us.

PREPARED STATEMENTS

Senator INOUYE. Without objection, your full statement will be made a part of the record. At this point I would like to include in the record any other statements we receive from Members of Congress.

[The statements follow:]

STATEMENT OF HON. VIC FAZIO

Mr. Chairman, I come to call your attention to an attempt by the Department of Health and Human Services to withhold refugee assistance funds appropriated by your Subcommittee without going through the recission process required by law. After looking at the circumstances of the Department's action, many members of the California delegation are forced to conclude that the withholding amounts to an impoundment of funds. We earnestly hope you will correct the problem.

The consequences of this impoundment would be very harmful to my State. Of the more than 600,000 refugees who have come to this country since 1975, roughly 46 per cent have chosen to settle in California. Many of them, of course, come from the Pacific Basin. Since 1981 we have had a 100 per cent increase in Indochinese refugees. During this same period federal support has dropped 25 per cent. Now, despite this increased burden, California's social service programming for refugees will be cut $2 million more. Though that seems a modest amount, it is about 12 per cent of the $16 million I believe we should qualify for. Worse, however, is a 40 per cent reduction in targeted assistance funding, from about $81.5 million to $51.5 million (plus another $11.5 million reduction from the general program for Florida specifically). In my own district this 40 per cent impoundment means Sacramento County's targeted assistance will drop from about $1.25 million to $840,000.

We understand that in the press of competing demands in the Congress it is tempting for Members from other states to consider this largely a California, or Florida, or coastal problem. In fact, I suspect that it was to isolate the cuts to smaller political constituencies that the Department chose to go about this de facto impoundment in the devious manner it did. Nonetheless, we would like to appeal to the rest of the Congress for some redress in what any objective analysis says is a national problem which has become a very localized burden. We also appeal to your sense that we should not be debasing a program which is entirely humanitarian in intent: cut the refugees, despite what the Congress has clearly said, because they are not registered to vote. Lastly, we believe you should be interested in the appropriations process itself.

Briefly, Mr. Chairman, the Department of Health and Human Services has proposed slashing refugee social service funding from $80 million clearly made available by the Congress in the 1984 continuing resolution to only $44.4 million. It did so by devising qualification criteria the Congress has rejected. Then, in a sleight of hand which must be motivated by tactical budget politics, they propose what they euphemize as a "combined allocation" of social service with targeted assistance programming. This rhetorical fig leaf is evidently meant to hint that there is some real synergistic bang for the buck achieved by a creative combination of social service with targeted assistance funding. In net effect, however, the action results in an ability to fund a hold-harmless approach to social services at the 90 per cent level while annihilating the targeted assistance program.

In their announcement of their approach to targeted assistance the Department rather blandly notes that "a total of at least $40 million in funds which the Congress has designated for this program is currently expected to be available for targeted assistance for refugees and entrants."

In other words, they simply slashed targeted assistance from $81.5 million to $51.5 million, then took another $11.5 million for Florida (which is appropriate) and hid their own action behind the passive phrase "is currently expected to be available."

We hope the Congress will prevent this impoundment, Mr. Chairman. Members of my delegation have asked the House Judiciary Subcommittee with refugee jurisdiction to hold oversight hearings. The Dean of our delegation has demanded an investigation of this action by the General Accounting Office. I attach a copy of his GAO letter to my testimony for your information. Clearly, however, this action most directly affects the House and Senate appropriations committees which appropriated funds the Administration is trying to take back. We should respond. I intend on making a similar case to your counterpart subcommittee in the House. I very much hope you can settle this matter.

Thank you.

March 29, 1984

Hon. Charles A. Bowsher
Comptroller General of the
United States
General Accounting Office
441 G Street, N.W.
Washington, D.C. 20548

Dear Mr. Bowsher:

I am writing to ask that you investigate the Administration's proposed FY 1984 funding of the Refugee Resettlement Program. I believe that the Administration's proposed allocations for social services under this program, as published in 49 Fed. Reg. 5383 (Feb. 13, 1984), amounts to an unreported and, therefore, unlawful rescission proposal under the Impoundment Control Act, 2 U.S.C. § 681.

In its February 13 publication, the Office of Refugee Resettlement (ORR) states that it

> expects to have available $44,400,000 in refugee/entrant social services funds and $81,500,000 in refugee/entrant targeted assistance funds. This determination has been made based upon an interpretation of the Second Continuing Resolution for FY 1984 (Pub. L. 98-151) as requiring that social service funding be recalculated using assumptions of refugee arrivals lower than those which were anticipated when the FY 1984 budget request was developed, and also as providing that targeted assistance funding be at the same level as in FY 1983.

I submit that this interpretation of the continuing resolution, reducing the social services appropriation significantly, amounts to an impoundment of funds.

Pursuant to Public Law 97-377, the Congress specifically provided $80 million for refugee/entrant social services in FY 1983. At the request of ORR, approximately $8 million of social services funding was later reprogrammed. Thus, the final allocation for social services in FY 1983 was $72 million.

Fiscal year 1984 funds were appropriated under Public Law 98-151, 97 Stat. 964. That continuing resolution states:

> (c) Notwithstanding any other provision of this joint resolution, except section 102, such amounts as may be necessary for continuing the following activities, not otherwise provided for in this joint resolution, which were conducted in the fiscal year 1983, under the terms and conditions provided in applicable appropriation Acts for the fiscal year 1983, at the current rate:
>
> . . .
>
> Refugee and entrant assistance activities under the provisions of title IV of the Immigration and Nationality Act, title IV and part B of title III of the Refugee Act of 1980, and sections 501(a) and (b) of the Refugee Education Assistance Act of 1980: provided....

97 Stat. 972. The language "under the terms and conditions provided in applicable appropriations Acts for fiscal year 1983, at the current rate" is Congress's clear statement that the appropriation for FY 1984 is to be not less than the amount appropriated in FY 1983, $80 million for social services.

Thus, ORR is, in my opinion, unlawfully withholding significant amounts of funds appropriated by Congress for social services through its continuing resolution for FY 1984.

In addition, Congress has been quite clear, indeed definitive, in its rejection of the ORR rationale used to reduce the amount actually appropriated by Congress. In both the House and Senate Reports on Public Law 97-363, the Refugee Assistance Amendments of 1982 (H. Rept. No. 97-541, S. Rept. No. 97-638), Congress rejected the Administration's 1983 social services authorization request as "inadequate and premised on an unsound theory." The reports reiterate that "the proper focus should be on the number of refugees who need such services, regardless of their date of entry." (emphasis added). S. Rept. at 5, H. Rept. at 8. Following the authorizing committees' rejection, the Appropriations Committees for FY 1983 rejected ORR's funding request of $59 million as inappropriate and appropriated instead $80 million based not on entry numbers but on actual program needs.

During the 98th Congress, the House Judiciary Committee's Report accompanying the Refugee Assistance Extension Act of 1983, H.R. 3729 (H. Rept. No. 98-404), stated that the Committee "flatly rejected the theory upon which the Administration's fiscal year 1983 social services budget request was made." The Report noted that the Committee was "disturbed" that the FY 1984 social services funding request was again based on anticipated flows, and reiterated that it saw "no basis in law or logic for such an approach." Once again the Committee asserted that "the proper focus should be on the number of refugees that need such services."

Even ORR admits the inadequacy of the $44 million to continue the activities conducted in fiscal year 1983. Specifically ORR states:

> ORR believes that the use of targeted assistance funds in a combined allocation with social services funds is an essential and appropriate response to the special programmatic needs of States in FY 1984....Also, supplementary funds would be targeted, under this proposal, to provide States with 90% of their FY 1983 formula allocations in order to avoid serious disruptions or terminations of services which would affect refugees currently receiving services or expected to need services during the year.

Fed. Reg. at 5383 (emphasis added).[1]

In conclusion, Congress has specifically appropriated FY 1984 funds "at the current rate" and has specifically and repeatedly rejected the ORR proffered rationale that would permit a recalculation of the appropriation "using assumptions of refugee arrivals." Finally, ORR admits that the recalculated amount is not even sufficient to fund the continuation of the services received in 1983, thereby necessitating the taking of funds from another program for a hold-harmless provision.

Due to the importance of these funds to State and local governments, your expeditious response would be greatly appreciated.

Thank you.

Sincerely,

Don Edwards

Don Edwards
Member of Congress

---

[1] ORR has proposed transferring $20 million from the targeted assistance program into social services. I understand, however, that as of this date no reprogramming request has been received by the Appropriations Committee.

STATEMENT OF SENATOR PATRICK LEAHY

I am concerned about two issues: 1) the use of the Quality Control System currently used by HHS to determine error rates upon which fiscal sanctions are applied in the Food Stamp, Aid to Families with Dependent Children, and Medicaid Programs, and 2) the Utilization of the Monthly Reporting System as a mangement tool in the AFDC and Food Stamp Programs.

QUALITY CONTROL AS FISCAL SANCTION TOOL

Last year, this Committee included language in the Conference Report for the FY84 Appropriations bill expressing concern that the current Quality Control Program upon which fixed sanctions are based, has serious deficiencies. Specifically, these deficiencies include reliability of current data, timeliness of the system to provide for corrective actions, relevance of geographic and socioeconomic differences to error rates, the inclusion of technical errors and client-caused errors in the error rate determinations, the fairness of a uniform national tolerance level, the use of various statistical measures, and assumptions of measuring error rates.

The Committee directed HHS to undertake a study of the Quality Control System and to coordinate this with the Department of Agriculture, allowing the greatest possible input from the states. The Committee asked HHS to report back to several committees, including the House and Senate Appropriations Committee on the outcome of the study, and to suspend fiscal sanctions against the states until the study was completed.

HHS responded by stating that no study was necessary and that they had no statutory authority to suspend sanctions. Both of these statements are debatable. However, Vermont can certainly demonstrate continuing problems with technical errors and the variability of interpretations of what constitutes an "error" by HHS, different regional offices, and sometimes by just a different federal reviewer looking at a case. The following example describes how a case in which child support was being collected was determined "ineligible."

> Two months prior to the month in which the case was examined, child support was collected in excess of the grant amount of the month reviewed. Even though no child support was subsequently collected, no money was lost, and there is no HHS policy upon which assistance could have been denied to this household, HHS still considered it an "error."

In Vermont, this one case can count as a whole percentage point when comparing performance to the target. Thus, it can mean the loss of several hundreds of thousands of dollars in federal money to the state.

It seems to me this points out problems with the Quality Control System as a tool to sanction states when, in reality, it results in shifting costs to the states and discourages good management.

MONTHLY REPORTING

States are struggling with attempts to implement requirements in the AFDC and Food Stamp programs to have recipients report eligibility factors monthly and to consider their circumstances based on that report retroactively, rather than prospectively. Vermont has been fortunate in having waivers approved to limit monthly reporting. The waivers were obtained upon demonstrating that total monthly reporting is not cost effective. However, limiting monthly reporting to those families with earnings has pin-pointed another problem - that of monthly reporting/retrospective budgeting being a dis-incentive to work. Monthly reporting and retrospective budgeting for the employed group made more sense prior to the cuts experienced by those with earnings caused by the Omnibus Reconciliation Act (OBRA) changes. With the OBRA changes, monthly reporting and retrospective budgeting was like the proverbial straw. Those terminated from assistance during the initial implementation of OBRA changes have not en masse come back on the rolls. But those with low earning capacity, mostly young women with young children, no skills, and various other barriers, are now hesitant to get jobs because the price is too high. If monthly reporting/retrospective budgeting is not made optional, at the very least, Secretary Heckler, I urge you to exercise your waiver authority as liberally as possible in recognition of this particular problem. Cost effectiveness should be looked at in terms of long-range social policy as well as today's dollars and cents.

I have attached a paper received from the Vermont Department of Social Welfare which provides further illustration of the problems caused by the Quality Control System as it is being used and interpreted by federal officials.

I am very concerned about this Catch 22 situation and the potential cost to the states. I respectfully ask that you reconsider the fairness of using quality control and monthly reporting as tools for sanctions. The system is not working well and I hope you will reconsider your position on these two matters.

CHILD SUPPORT ERRORS

Vermont has operated an excellent Child Support Enforcement program for eight years. The state has frequently been cited during this time for running a model Child Support collections system.

In all of this time, the system has been a regular part of both state and federal Quality Control Reviews, with no errors resulting from Child Support collections exceeding the monthly grants.

In February, 1984, Vermont received a variance on a March, 1983 ANFC Quality Control case which the state had judged a correct payment (variance attached).

After eight years, regional ANFC Quality Control has apparently decided to abandon logic and to start building up Vermont's error rate with another series of technical errors. In conference recently, federal Quality Control officials informed Vermont's Quality Control officials that they had had to correct other states Child Support Quality Control problems and they were finally getting to Vermont. This was the response to our question of why after eight years this was suddenly an issue.

Vermont does not agree with the first variance nor indeed with the federal interpretation of how to apply the Quality

Control rules covering the Child Support payment issue. We intend to continue to apply logic in each individual case.

For example, the federal officials agree that the Child Support collections issue is the only instance in ANFC Quality Control where a case can be called incorrect when the case is perfectly accurate during the sample month.

This happens because the federal interpretation of the Quality Control rule is that the child support collected two months before the Quality Control review month is applied to the review month's grant irregardless of what happened in the interim months. This is the only instance in Quality Control where a case can be called incorrect on data two months old.

The following charts illustrate the situation as viewed by Vermont and by Federal Quality Control:

Clients Grant Amount	Month 1 $300.00	Month 2 $300.00	Month 3 $300.00 QC Month
Child Support Collected	Month 1 $400.00	Month 2 $ 50.00	Month 3 Zero QC Month

Vermont's position is that if the $400.00 Child Support collections had continued for all three months, the case would be in error. But, since the child support payments did not continue there was no reason to close the case and the case was, in fact, eligible and correct in Month 3, the QC Month sampled.

The new federal interpretation is quite simply shown by the following charts:

Clients Grant Amount	Month 1 $300.00	Month 2 $300.00	Month 3 $300.00 QC Month
Child Support Collected	Month 1 $400.00	Month 2 ?	Month 3 ? QC Month

The federal Quality Control officials are stating that the payment in Month 3, the QC Month, is ineligible based solely on the child support collected in Month 1. The child support activity in Month 2 and Month 3 is completely ignored.

Vermont takes the position that this is an absurd way to operate a Quality Control program and we intend to continue to call cases inaccurate only when the facts support such a decision. We will not call cases inaccurate by rate and arcane formula as our regional Quality Control officials are dictating. This means of course that the federal officials will now pad Vermont's ANFC error rate with a new (for Vermont) type of technical error dollar amount, heavily inflated by their regression formula. We can only look forward to countless appeal process setbacks until we can finally get the cases into a true court where law and logic have an equal chance.

Ironically, if the child support payments were going to the client instead of being collected by the Agency in the example outlined above, the case would not be in error. The same payments going to the Child Support Agency would have been called contributions if they were going directly to the client, and, because they stopped before the QC Month, Month 3, the case would be judged correct by both state and federal QC.

We are disturbed in Vermont that the Regional Quality Control will not assist the state in solving real issues and instead pursue such dubious errors with enthusiasm.

Prepared by the Vermont Department of Social Welfare

NONDEPARTMENTAL WITNESSES

STATEMENT OF JOHN F. HUDACS, EXECUTIVE DEPUTY COMMISSIONER OF LABOR, NEW YORK DEPARTMENT OF LABOR

PREPARED STATEMENT

Senator INOUYE. Our next witness is John F. Hudacs, executive deputy commissioner of labor of the New York Department of Labor.

Welcome, Mr. Commissioner.

Mr. HUDACS. Thank you, Mr. Chairman.

Senator INOUYE. Your full statement will be made a part of the record at this point, and you may proceed.

[The statement follows:]

STATEMENT OF JOHN F. HUDACS

WAGNER-PEYSER FUNDING

New York State has suffered the greatest percentage loss in funding of any state in the nation, from 10.2% of national program in FY 1983 to 7%, as a result of the revisions to the Wagner-Peyser funding formula.

To maintain the FY 1983 level of 1,873 positions (already reduced from 2,007 positions in FY 1982), allowing for an 8% pay raise and cost of inflation adjustment would require an annual allocation of approximately $69,451,000 ($52,090,000 for the nine month fiscal year). NY State received an allocation of $48,336,346 for the period October 1, 1983 to June 30, 1984 including a discretionary allocation from the Secretary. This will support an estimated 1,723 positions.

Recommendations

1. The JTPA amendment to Wagner-Peyser providing for a 90% funding hold harmless should be changed to a 95% hold harmless for two year for NY State and approximately 6 other states most seriously impacted. By increasing the hold harmless level for two program years, the State can better adjust to reduced funding levels with less major disruption and fewer staff layoffs.

    a. In Program Year 1984, under a 95% hold harmless provision, New York State would receive an allocation of $65,397,163 versus the actual allocation of $62,400,300.

    b. In Program Year 1985, under a 95% hold harmless, New York State would receive an estimated $64,624,064 versus the estimated allocation at 90% hold harmless of $58,619,557.

2. The new Wagner-Peyser funding formula has already been applied to the Fiscal Year that began October 1, 1983. Its net effect was to cause the loss of some 150 staff positions to the Wagner-Peyser placement program. We request a supplemental appropriation for the current fiscal year of $2,586,895 to a revised total of $50,923,241 (95% hold harmless).

These two actions would enable New York State to transition to a reduced allocation level with less drastic impact on those who need our capability.

UNEMPLOYMENT INSURANCE PROGRAM (NON PERSONAL SERVICE COSTS)

The current magnitude of funding reductions in the benefit payment and fraud control system must result in reduced services to claimants and employers, increase in the error rate, and less effective fraud control operations.

Recommendations

Three actions are considered necessary:

1. For FY 1985, a shift of $50 million should again be made from the contingency fund to the base allocation.

2. Allocation of one time discretionary federal funds to afford New York State the opportunity to implement reductions to nonpersonal services such as premises expenses, travel, supplies, equipment and communications. A major portion of these costs are fixed and we have very limited ability to eliminate or substantially reduce these costs in a short period of time.

3. In addition, the current method of allocating NPS funds (if necessary, through legislation) must be revised to provide for a resource allocation which insures adequate funding of each state's base requirements. To assist in alleviating this problem, states should be authorized to use contingency funds for non personal services.

Dimensions of the Current Problem

- New York State's expenses for FY 1984 for premises, communication and equipment rentals are estimated at $16.5 million. This amount represents 78% of the total estimated annual costs of $21,050,000 for all nonpersonal services expenses for operation of the Unemployment Insurance program. These fixed costs alone exceed the available allocation of $14.8 million by $1.7 million, and represent the cost to maintain the existing statewide office network.

- In the nonpersonal service area, resources are being shifted on an average cost per position basis. This method fails to recognize that states have fixed costs which do not fluctuate in a direct proportion to the number of base positions allocated. States which gain under the formula do not add nonpersonal service costs in a direct proportion to positions being added, particularly in fixed cost items. Prior to this change in the method of resource allocation, a model was utilized which afforded greater consideration to each state's fixed costs requirements.

- The effect of the NPS formula on New York State has been dramatic. From FY 1982 to FY 1984, total annual equivalent positions in New York State went from 4,235 to 3,967, for a total reduction of 268 positions. The NPS allocation per position was reduced from $4,607 to $3,728.

- During 1984, approximately 26 states will not require above base earnings to fund their programs. Other states must rely more heavily on the earnings above base both for staff and nonpersonal services. Since the above base is funded at a lower rate than the base, there is a built-in inequity in the final allocation process. Failure to correct this deficiency in the formula will lead to even greater problems in the future.

JOB TRAINING PARTNERSHIP ACT (JTPA)

The reduction of federal funds has had severe repercussions on employment and training activities. The following table depicts the declining funding level in N.Y. State for employment and training programs.

TABLE I

Program	Year	Funds	Participants
CETA	FY'81	$580,791,000	264,800
CETA	FY'82	272,324,000	158,810
CETA	FY'83	230,325,000	128,000
JTPA	PY'84	184,724,000	123,050

- The decrease from the last full year of CETA compared to the first full year of JTPA will be $46 million.

- Under JTPA, New York State has lost $400 million and the ability to serve approximately 150,000 individuals in a three-year period. Using even the simplest economic multiplier effect, the result is a loss of $1 billion and 300,000 jobs for the New York State economy from FY 1981 to the present.

- During FY 1981, CETA resources permitted serving approximately 13% of the estimated 2 million persons annually who qualify for and could benefit from employment and training services in New York State. JTPA resources will serve only 6% of this universe, despite the lower unit costs under JTPA (no training stipends or public service employment).

Recommendation

Because major studies of the outcomes of training expenditures have consistently established such public investments as cost effective, national policy and appropriations levels should address the need to serve a more significant percent of those who can benefit from such services.

WORK INCENTIVE PROGRAM (WIN)

The WIN program is an important part of the effort to reduce structural unemployment. Nationally, every WIN dollar spent results in a greater than two dollar savings in welfare expenditures.

For the last seven months New York State has been operating a pilot modified WIN program in cooperation with USDOL which has resulted in a fourfold increase in the percentage of those obtaining employment. This new approach has:

- reduced paperwork by 98%;
- streamlined the referral of registrants to JTPA and other training programs for classroom and on-the-job training;
- targeted scarce resources to those recipients with fewer placement barriers;
- resulted in over two-thirds of all job placements from direct WIN staff efforts by working with clients on a one-to-one basis.

Recommendations

1. The WIN program should be continued at a national funding level of $280.5 million during FY 1985.

2. FY 1984 supplemental funds should be provided to New York State to expand the modified WIN approach to a fully statewide program. Consideration to expand the New York State model for nationwide implementation should be explored by USDOL.

TRADE ACT OF 1974 (TA)

- In FY'83 the New York State Job Service approved training under the Trade Act for 1,539 eligible individuals. Approximately 500 additional individuals were not approved because of lack of funds.

- Congress appropriated $29.7 million for TA activities in FY'84. We understand that the States, in response to a request from USDOL for needs assessments, indicated requirements in excess of $55 million to meet anticipated needs.

- Halfway through the fiscal year 1984, New York State has been allocated $655,646. We are informed that an additional $718,000 in funding is pending which consists of $450,000 from JTPA and $268,000 from Trade Act. This compares with expenditures of $4.7 million during FY 1983.

- The Executive Budget for FY'85 contains no specific funding for the Trade Act, recommending that the Trade Act be transferred to JTPA under the Title III Displaced Workers program.

- The Trade Act was designed to compensate workers who are unemployed as a result of the Federal government's foreign trade policies and not as a result of the dynamics of the American economy. Title III guidelines, eligiblity requirements and legislative intent differ from TA, subjecting eligible workers to competition for limited Title III funds.

Recommendation

New York State is opposed to transferring the Trade Act to Title III. We recommend refunding the Trade Act at not less than $30 million for FY 1985.

TARGETED JOBS TAX CREDIT PROGRAM (TJTC)

- New York State employers have led the nation in the utilization of TJTC to provide jobs for disadvantaged workers.
- Since the inception of the program through September 30, 1983, the TJTC program has resulted in 83,711 jobs for disadvantaged New Yorkers, with a potential value of $376.7 million in tax credits to the private sector.
- TJTC Tax Credits can correlate to job creation. The Golub Corporation, a 58 store supermarket chain, has been participating in TJTC since 1980. The Corporation's TJTC coordinator estimates that the newest and largest of their stores, employing 200 people, was made possible by a company investment almost comparable to their total and anticipated tax credits.
- The New York State Job Service Marketing Strategy has produced an increase in certifications excess of 68%; from 18,001 in '82 to 30,181 in '83. Certifications for '84 are already increased by 112% compared to this period in '83.
- FY'84 administrative funding of $1.4 million for New York State provides for only administrative and processing positions. The reduction in Wagner-Peyser funding compounds the staffing problem. It is no longer possible to assign local office staff on a temporary basis to handle peaks in Local Office program activity.
- Federal directives require that NYSDOL issue employer certifications within 72 hours of receipt of request. Despite the effective simplicity of New York's Certification process, the volume of transactions has created a four-week backlog. Delays in the issuance of certifications and more importantly, certification denials, hinder program effectiveness.
- TJTC Administrative resources are utilized only for the certification and voucher process. Promotion of TJTC is handled through UI mailings to employers and other existing channels.

Recommendation

New York State is currently expanding approximately four times its administrctive allocation of $1.4 million to operate TJTC.

We recommend that the administrative allocation be increased for FY 1985 to $5.6 million for the continued effective operation of this important program and the national allocation adjusted accordingly.

We further request a supplemental appropriation for FY 1984 to permit adequate operation of the program in all states.

Mr. HUDACS. Thank you. I have an abbreviated version.

My name is John Hudacs. I am the deputy commissioner of labor of the New York State Department of Labor. I am appearing on behalf of Lillian Roberts, and I appreciate the opportunity to comment before you and comment briefly upon projects that have major impact to the people of New York State.

These are the Wagner-Peyser Program, the Unemployment Insurance Program, the Job Training Act Partnership Program, and the Trade Act of 1974.

As a result of the Wagner-Peyser funding, New York State has suffered the greatest percentage loss in funding of any State in the Nation, 10.2 percent of the national program in 1983 to 7 percent. The program will substantially impact individuals that can be rendered placement assistance.

The new Wagner-Peyser funding formula has already been applied for fiscal year, October 1, 1983, and in New York the net effect was the loss of approximately 150 staff positions. In addition to that, we lost another 134 positions the previous year. And, in the coming months, we will lay off another 55 individuals.

We strongly suggest that the JTPA funding for Wagner-Peyser be changed to 95 percent hold harmless so that New York State and the other 12 States most seriously impacted can receive some sort of a bridge effect in dealing with this particular problem.

Senator INOUYE. What are the other 12 States?

Mr. HUDACS. I can provide you with a list. Hawaii is one of them.

Senator INOUYE. Hawaii is one of them?

Mr. HUDACS. Originally, it was 6 States for the past fiscal year, but it has now been expanded in terms of our extrapolations to include 12 States and New York, which would make it 13.

By increasing the hold harmless level for at least 2 program years, these States can better adjust to reduced funding levels with less major disruption and fewer staff layoffs.

We also would ask that consideration be given for supplemental appropriation for the current fiscal year of $2.6 million in terms of New York State's needs, and this would bring us to a 95-percent hold harmless.

This would help cover the cost of a 7- or 8-percent pay raise, which is negotiated in collective bargaining with public employees and which becomes effective April 1, 1984. It would also cover the increased costs of inflation which are not provided in our current allocation, even when we consider that the Secretary of Labor's discretionary allocations have been made.

The total estimated cost by our computation is to return all of the 13 States to the 95-percent save harmless rather than a 90-percent save harmless, and that is about $6.6 million.

We also ask that consideration be given to adequate funding for the unemployment insurance situation. The current magnitude of funding and fraud control system must result in reduced services to claimants and employers and an increase in the error rate and less effective fraud control operations, which is a particular problem to us.

Senator INOUYE. Before proceeding, I hope you realize that this committee cannot change the formula from 90 to 95. That is before the authorizing committee.

Mr. HUDACS. I understand that.

Senator INOUYE. What we will do is we will notify the authorizing committee of your concerns. Legislatively, we cannot do it.

Mr. HUDACS. There are several things that we would propose that can be done administratively by U.S. Department of Labor, but we have found that they have been very reluctant to do that in some instances, citing that there is an ambiguity in the law. Though our interpretation is that they could do it, they feel that they need some type of legislative action.

So we have tried to make these points made known to the various congressional delegates from New York so that they can work with us, with the U.S. Department of Labor, to try and resolve these things and, if a statement of congressional intent is appropriate in some form, that it be included.

Senator INOUYE. You think some language in the committee report urging the Department to do likewise may be helpful to you?

At this stage it may be a bit too late to have authorizing legislation passed, but we will try.

Mr. HUDACS. We appreciate it.

In the unemployment insurance area, the problems that we are being confronted with are also being confronted by 15 to 17 other States in nonpersonal services.

Fixed costs for premises, communications, and dedicated computer lines for our computer services, and equipment rentals alone exceed the available allocation of $14.8 million by $1.7 million.

The effect of the nonpersonal services formula in New York State has been dramatic. From fiscal year 1982 to fiscal year 1984, the total annual equivalent positions in New York State went from 4,200 to 3,900 positions, a total reduction of 268 positions. In this nonpersonal services, allocation per position was also reduced from $4,600 to $3,700.

The average cost per position method, which is used by the U.S. Department of Labor, fails to recognize that States have fixed costs that do not fluctuate in direct proportion to the number of base positions allocated.

The personal expenditures, on which we have very, very little control, we would like to recommend that for fiscal year 1985 a shift of $50 million also be made by Congress, as was done last year, from the contingency fund to the base allocation.

We also recommend an allocation of one-time discretionary funds to afford—for example, New York State in this particular instance—the opportunity to implement reductions to nonpersonal services, such as premises expenses, communications, and deal with it in a more realistic way. A major portion of these costs are fixed, and we have a very limited ability to eliminate or substantially reduce these costs over a very short period of time, although given time we can do it.

In addition, the current method of allocating nonpersonal services funds must be revised to provide for resource allocation that ensures adequate funding for each State's base requirements.

We would also recommend that to assist in alleviating the problem States should be authorized to use contingency funds for nonpersonal services.

If these actions are taken, then I think we can bridge the problem that we have now, which in its present sense and immediacy of it is rather overwhelming. We can reduce nonpersonal services cost, but the bridge effect that is required makes it exceptionally difficult with agreements that have been entered into, with raising costs of telecommunications requirements for our computers, and so forth. We need a little more time to achieve those results.

In the last 7 months New York State has been operating a pilot modified WIN Program, a Work Incentive Program in cooperation with the U.S. Department of Labor. This has resulted in a fourfold increase in the percentage of those obtaining employment.

This cooperative venture between the New York State Labor Department, the New York State Department of Social Services, and the U.S. Department of Labor is very, very encouraging to us. It has reduced paperwork; it has streamlined the referral of registrants to the Job Training Partnership Act, SDA, from the PIC's, and other training programs for classroom and on-the-job training. It has resulted in over two-thirds of all job training placements from WIN staff efforts in working with clients on a one-to-one basis.

We would recommend that the WIN Program be continued and the funding level of $280 million, which is basically the range that it is at today. be continued for fiscal year 1985, and we urge in fiscal year 1984 that supplemental funds be provided to expand our modified WIN Program to a full statewide program.

Expansion of this modified WIN to an additional 22 counties in the State would require $1 million for staff services, in OGT. That consideration should be given to expand this New York State model for nationwide implementation. We have been urging U.S. Department of Labor to do that, and we have been encouraged by the response.

Another program that is of particular interest was the Trade Act of 1974. In fiscal year 1983, the New York State Job Service approved training under the Trade Act for 1,539 eligible individuals. We had another 500 individuals who were not approved because of a lack of funds.

Congress, last year, appropriated $29.7 million in TA activities for fiscal 1984. The executive budget for 1985 contains, however, no specific funding for the Trade Act. The recommendation is that the Trade Act be transferred to the job training partnership under the title III Displaced Workers Program. We urge that this not take place, and we urge that Congress refund the program at least to its present level.

The Trade Act was designed to compensate workers who are unemployed as a result of the Federal Government's foreign trade policy and not as a result of the dynamics of the American policy.

Title III guidelines eligibility requirements and legislative intent differ from the Trade Act, subjecting eligible workers to competition from very limited title III funds.

One of the last programs I would like to comment on is the Targeted Jobs Tax Credit Program. New York State employers have led the Nation in the utilization of the TJTC to provide jobs for disadvantaged workers.

Since the inception of the program, since 1983, the TJTC Program has resulted in 83,000 jobs for disadvantaged New Yorkers due to the New York State Job Service marketing strategy and a simplified administrative procedure for employees that we have initiated. We have during 1983 increased certifications by 68 percent, and in 1984 we have increased by 112 percent certifications compared to this period in 1983.

The fiscal year 1984 administrative funding of $1.4 million from New York State provides for only administrative and processing decisions.

The reduction in Wagner-Peyser, which I mentioned earlier, compounds our staffing problem. It is no longer possible to assign local office staff, even on a temporary basis, to handle peaks in local office program activity. Federal directives, for example, require that New York State DOL, the Department of Labor issue employer certifications within 72 working hours of the receipt of the request. Despite the simplicity of our certification process, the volume of transactions has created a 4-week backlog due to inadequate staff levels.

New York is currently spending four times its administrative allocation of $1.4 million to operate the targeted job tax credit. We believe it is a valuable program to employers and employees who seek and acquire employment opportunities through it. We would recommend that the administrative allocation be increased for fiscal 1985 to $5 million to continue the effect of this program and that the national allocation be adjusted accordingly.

Senator INOUYE. Mr. Hudacs, I will have to, most reluctantly, cut you off at this point, and I would like to announce to the other witnesses, the committee wishes very much to complete our consideration of this bill in a timely manner so that we can pass an appropriations bill this year.

We think it is much better than having a continuing resolution like we had in the past, and so, much as we hate to do so, we have allocated time. But I can assure you that your full statements will be made part of the record.

I can assure you that most of us in the committee will take time to read your statement, and I can guarantee you that the staff will study your statement very carefully.

So, Mr. Hudacs, I thank you very much.

Just one thing for the record, what is your unemployment rate at this time?

Mr. HUDACS. At this time the adjusted unemployment rate is 6.9 percent statewide. New York City exceeds that by about a percentage and a half.

Senator INOUYE. Thank you very much.

Our next witness is Mr. Dave Affeldt, the assistant legislative council of the American Association of Retired Persons.

STATEMENT OF DAVID AFFELDT, ASSISTANT LEGISLATIVE COUNSEL, ASSOCIATION OF RETIRED PERSONS

ACCOMPANIED BY SAMUEL J. SIMMONS, PRESIDENT, NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

Mr. AFFELDT. I am also accompanied by Samuel Simmons, president of the national caucus and Center on Black Aged, Inc. I would ask that he testify before me because he has testimony at 11 o'clock.

Senator INOUYE. I know these lights are distracting, but this is the only way we can do it. This is like the Supreme Court of the United States.

Please proceed.

Mr. SIMMONS. Mr. Chairman, the NCBA welcomes the opportunity to testify here today on funding for programs affecting aged blacks and other older Americans.

NCBA recognizes that the Congress plans to take significant steps to reduce our mounting budget deficit. We sincerely hope that the major thrust will focus on closing gaping loopholes in our tax laws and holding defense spending to more manageable proportions.

NCBA does not believe that every single domestic program should be cut back or held in check. Certain activities deserve well-timed and well-conceived funding increases because of special circumstances, national priority goals, or overriding needs to be met. This is true, even though the overall Federal budget may be reduced substantially in fiscal year 1985.

NCBA is offering these proposals to the subcommittee. All of these measures affect the Older Americans Act. Two relate to one program, the title V Senior Community Service Employment Program.

First, NCBA urges the subcommittee to approve a $2.15 million increase for the title V SCSEP in the fiscal year 1984 Spring Supplemental Appropriations Act. This would boost funding from $317.3 million to $319.45 million, effective July 1, 1984.

Title V is currently funded at $319.45 million, which is $22.95 million above its fiscal year 1983 authorized ceiling because Congress, in effect, provided a waiver for the SCSEP in the emergency jobs law, Public Law 98–8.

Fiscal year 1984 funding is currently at the authorized cap, $317.3 million.

If this figure remains unchanged, there will be a reduction in the number of temporary enrollees in the program, authorized positions, or average hours per enrollee.

NCBA considers either of these alternatives to be undesirable. A $2.15 million supplemental appropriation for title V in fiscal 1984 can help assure that this enormously successful program continues to operate effectively and without disruption.

This becomes all the more important now because poverty is on the rise for persons 55 and older. Moreover, older workers are still experiencing hard times in the job market, despite recent improvements in the overall employment picture. In the case of many blacks, 55 or older, they are either in a serious economic recession or depression.

Second, NCBA favors full funding for the SCSEP in fiscal 1985. At this time we are unable to provide a precise figure because the House and Senate have not yet approved an Older Americans Reauthorization Act in final form.

We anticipate, though, that the final authorization will be about $335 million to $340 million. Currently, title V has 62,500 authorized positions. A $335 million appropriation would fund about 65,550 jobs. If it is $340 million, it would be 66,500.

However, the number of persons actually participating in the program is actually 1½ to nearly two times the authorized positions, essentially for two reasons: Many of the title V enrollees are transitioned into unsubsidized jobs, and the administrative cost for this program is low.

These two developments enable more low-income older Americans to participate in the program. Consequently, full funding for the program would probably provide more than 100,000 jobs, and nearly all of these low-income participants would have income below the poverty line.

Title V has been an extraordinarily effective program. Numerous low-income older Americans are ready, willing, and able to participate in the program.

In fact, NCBA frequently has several applicants for each position; and we could have more if we did additional advertising. But we do not because this would only cause great disappointment for those whose hopes were raised when there was no realistic opportunity for a job.

Quickly I'd like to change to title IV, research, training, and demonstrations. NCBA further supports a $26 million appropriation for title IV research. This is $3.8 million above the current level.

We are opposed to the $5 million budget request which would, in effect, kill title IV. Last year the Congress rejected an identical proposal. We sincerely hope that both the Appropriations Committee and the House will do the same.

We are proposing a modest increase to offset major reductions in research, training, and demonstrations necessitated, in large part, because of the 1981 Omnibus Budget Reconciliation Act.

Funding has been cut in this program by 59 percent to $22.2 million in fiscal 1984. Moreover, the $3.8 million appropriations increase would permit some modest growth in key areas, including support of aging programs at historical black colleges and universities, expanded career preparation training for persons to serve in the field of aging, additional demonstrations in areas to benefit older minorities, and other activities.

The comparatively small amount expended for title IV has produced major dividends for our Nation over the years. Some of the most successful programs in the field of aging evolved from demonstrations such as the Nutrition Program, Foster Grandparents, and the Retired Senior Volunteer Program.

Title IV training programs have produced qualified personnel to fill services positions for the elderly and research activities have yielded much valuable information for policymakers, practitioners in the field of aging, older Americans, and the public at large.

In conclusion, we have enjoyed your support in the past and look forward to working with you and making life better for older people in this country.

PREPARED STATEMENTS

Senator INOUYE. Nothing has changed since your last testimony. I thank you very much.

Your complete statements will be made a part of the record.

[The statements follow:]

STATEMENT OF SAMUEL J. SIMMONS

Mr. Chairman and members of the Labor, Health and Human Services, and Education Appropriations Subcommittee, the National Caucus and Center on Black Aged welcomes the opportunity to testify here today on funding for programs affecting aged Blacks and other older Americans.

NCBA fully recognizes that the Congress plans to take significant steps to reduce our mounting budget deficit. We sincerely hope that the major thrust will focus on closing gaping loopholes in our tax laws and holding defense spending to more manageable proportions.

NCBA does not believe that every single domestic program should be cut or held in check. Certain activities deserve well-timed and well-conceived funding increases because of special circumstances, national priority goals, or overriding needs to be met. This is true, even though the overall federal budget may be reduced substantially in fiscal year 1985.

NCBA is offering these proposals to the Subcommittee. All of these measures affect the Older Americans Act. Two relate to one program--the Title V Senior Community Service Employment Program.

Supplemental Increase for Title V Senior Community Service Employment Program (SCSEP)

First, NCBA urges the Subcommittee to approve a $2.15 million increase for the Title V SCSEP in the Fiscal Year (FY) 1984 Spring Supplmental Appropriations Act. This would boost funding from $317.3 million to $319.45 million, effective July 1, 1984.

Title V is currently funded at $319.45 million, which is $22.95 million above its FY 1983 authorized ceiling because Congress, in effect, provided a waiver for the SCSEP in the Emergency

Jobs law, Public Law 98-8. FY 1984 funding is currently at the authorized cap: $317.3 million.

If this figure remains unchanged, there will be a reduction in the number of temporary enrollees in the program, authorized positions, or average hours per enrollee. NCBA considers either of these three alternatives to be undesirable. A $2.15 million supplemental appropriation for Title V in FY 1984 can help assure that this enormously successful program continues to operate effectively and without disruption.

This becomes all the more important now because poverty is on the rise for persons 55 or older. Moreover, older workers are still experiencing hard times in the job market, despite recent improvements in the overall employment picture. In the case of many Blacks 55 or older, they are either in a serious economic recession or depression.

FY 1985 Funding for Title V SCSEP

Second, NCBA favors full funding for the SCSEP in FY 1985. At this time, we are unable to provide a precise figure because the House and Senate have not yet approved an Older Americans Act reauthorization bill in final form.

We anticipate, though, that the final authorization will be about $335 million to $340 million. Currently, Tile V has 62,500 authorized positions. A $335 million appropriation would fund about 65,550 jobs. And, a $340 million funding level would provide 66,500 jobs for low-income persons 55 or older.

However, the number of persons actually participating in the program is 1½ to nearly 2 times the authorized positions essentially for two reasons:

-- Many Title V enrollees are transitioned into unsubsidized jobs; and

-- Administrative costs for the program are low.

These two developments enable more low-income older Americans to participate in the program. Consequently, full funding for the SCSEP would probably provide more than 100,000 jobs, and nearly all of these low-income participants would have income below the poverty line.

Title V has been an extraordinarily effective program. Numerous low-income older Americans are ready, willing, and able to participate in the program. In fact, NCBA frequently has several applicants for each position available. And, we could have more if we did additional advertising. But, we do not because this would only cause great disappointment for those whose hopes were raised when there was no realistic opportunity for a job.

For these reasons, we reaffirm our support for full funding in FY 1985 for the SCSEP.

Title IV Research, Training, and Demonstrations

NCBA further supports a $26 million appropriation for Title IV research, training, and demonstrations. This is $3.8 million above the current level. We are opposed to the $5 million budget request, which would, in effect, kill Title IV. Last year the Congress rejected an identical proposal. We sincerely hope that both the Appropriations Committee and the House will do the same.

We are proposing this modest increase to offset major reductions in research, training, and demonstrations--necessitated in large part because of the 1981 Omnibus Budget Reconciliation Act. Funding has been cut by 59 percent for Title IV, from $54.3 million in FY 1980 to $22.2 million in FY 1984. Moreover, the $3.8 million appropriations increase would permit some modest growth in key areas, including support for aging programs at historical Black colleges and universities, expanded career preparation training for persons to serve in the field of aging, additional demonstrations in areas to benefit older minorities, and other activities.

The comparatively small amount expended for Title IV has produced major dividends for our nation over the years. Some of the most successful programs in the field of aging evolved from demonstrations, such as the nutrition program, Foster Grandparents, and the Retired Senior Volunteer Program. Title IV training programs have produced qualified personnel to fill services positions for the elderly. And, research activities have yielded much valuable information for policymakers, practitioners in the field of aging, older Americans, and the public at large.

Conclusion

In conclusion, we wish to commend the Subcommittee for its past action on behalf of aged Blacks and other older Americans. You obviously have a difficult task because many groups are seeking additional funding. You have been fair, responsive, and fiscally responsible in performing your duties.

NCBA believes our proposals are reasonable and much-needed. We look forward to working with the Subcommittee. And, we urge the Subcommittee to approve these measures.

STATEMENT OF DAVID AFFELDT, ASSISTANT LEGISLATIVE COUNSEL, REPRESENTING JAMES M. HACKING, ASSISTANT LEGISLATIVE COUNSEL, AMERICAN ASSOCIATION OF RETIRED PERSONS

PREPARED STATEMENT

Senator Inouye. Our next witness is Mr. David Affeldt. At this time, your complete statement will be made a part of the record.

[The statement follows:]

STATEMENT OF DAVID AFFELDT

Mr. Chairman and Members of the Subcommittee, the American Association of Retired Persons appreciates the opportunity to testify at this hearing. At the outset, we want to commend you for your past support of programs to serve the elderly. You have responded fairly, compassionately, and in a fiscally responsible manner.

As you have requested, we shall keep our statement brief. The Association has essentially six proposals to offer to the Subcommittee.

A. FY 1874 Funding for Senior Community Service Employment Program

One of the highest priorities is to provide a $2.15 million increase for the Title V Senior Community Service Employment Program in FY 1984. We urge that this modest funding boost be included in the FY 1984 Spring Supplemental Appropriations bill or other appropriate vehicle.

This increase is needed now because there will be a reduction in the number of temporary enrollees or positions without a supplemental appropriation. Title V is funded at $319.45 million for the 1983-84 program. This is almost $23 million above the FY 1983 ceiling because the Emergency Jobs law allowed the SCSEP appropriation to exceed its authorized cap.

Title V is funded at $317.3 million for FY 1984, which is the full amount of the authorization. FY 1984 begins on July 1, 1984, for the SCSEP since it is forward funded by nine months. AARP expects the Older Americans Act reauthorization bill, which will probably become law soon, to raise the FY 1984 authorized ceiling for Title V to at least $319.45 million. This would pave the way for a $2.15 million supplemental increase for the SCSEP.

B. Full Funding for SCSEP in FY 1985

AARP further supports full funding for the SCSEP in FY 1985. As you know, action is not yet complete on the Older Americans

Act reauthorization bill. However, AARP expects the minimum authorization to be at least $331.9 million, and quite likely higher.

Title V now has 62,500 authorized positions. However, the need is much greater, for the following reasons:

-- Unemployment still remains high by historical standards for older Americans. This does not even take into account the "discouraged" workers and the "hidden unemployed.

-- Poverty is on the rise for persons 55 or older, especially for those 55 to 64 years. Many of these individuals have become unemployed and have exhausted their unemployment benefits.

-- Large numbers of low-income older Americans are ready, willing, and able to serve in their communities if given the opportunity.

C. Increased Funding for Nutrition Program for the Elderly

AARP also recommends a $15 million increase for the nutrition program for the elderly -- $10 million for the congregate meals program and $5 million for home-delivered meals.

This would boost funding from $321.6 million to $331.6 million for the congregate meals program and from $62 million to $67 million for the home-delivered meals. This is needed to compensate for anticipated inflation and to permit more older Americans to participate in these extraordinarily effective programs.

The congregate meals program, for example, provides more than just a nutritious meal. It also offers an opportunity for older Americans to meet and talk with others. This is especially valuable for single aged persons with few close friends.

In addition, the home-delivered meal program has enabled many older Americans to continue to live independently in their homes, rather than be placed in a nursing home at a much higher public cost.

D. Title IV Research, Training, and Demonstrations

Our final funding proposal for the Older Americans Act is a $26 million appropriation for Title IV research, training, and demonstrations. This is $3.8 million above the existing amount. We recommend that this additional funding be used to bolster the following activities:

- -- The long-term care gerontology centers program should have at least one center in each of the ten HHS regions.
- -- The national legal services demonstration program should be expanded to provide more innovative approaches to delivering legal services to the elderly.
- -- Career preparation training program should be expanded to enable more persons to work in the field of aging, especially minorities.
- -- Demonstrations should be increased, particularly projects to assure more equitable treatment for older minorities, to assist the rural aged, and to provide services for those afflicted with Alzheimer's disease as well as their families.

E. Low Income Home Energy Assistance Program (LIHEAP)

Another high priority for AARP is a substantial increase in funds for the LIHEAP, from its current appropriation of 2.075 billion to at least $2.3 billion in FY 1985. Increased appropriations are needed to address the inadequacy of present funding levels, the growing demand for assistance, and continued escalation in home fuel prices.

LIHEAP is an extremely important program for low income older Americans, who along with all elderly persons, are exceptionally vulnerable to hypothermia and heat stroke. Some forty to forty-five per cent (40 - 45%) of households served by the program contain at least one elderly member. Still, only one-third of eligible households receive assistance.

Demand for home energy assistance is growing because of more severe weather, increasing residential costs (heat expenses for low income households in the North Central U.S. are expected to rise by 15% over the 1983-4 winter season), increasing utility arrearages and shutoffs, and spreading word of the program's existence. Despite increased demand, the number of households served by LIHEAP has dropped from 7.1 million in FY 1981, to a projected 6.6 million in FY 1984 (estimated by states prior to enactment of HJ Res. 493).

Funding has been inadequate for LIHEAP from the start. In 1980, the Home Energy Assistance Program was authorized at $3.1 billion, with increases built in for outlying years, yet spending for this critical program has never risen above the current $2.075 billion level. The $2.3 billion the Association seeks for FY 1985 is compatible with the major reauthorization proposals now pending. Under no circumstances should the FY 1985 appropriation be reduced below the current level of $2.075 billion.

F. Title XX Social Services Block Grant (SSBG)

AARP is very pleased that the Administration has requested the full $2.7 billion authorized for the Title XX/Social Services Block Grant in FY 1985. This is still less than the $2.9 billion level at which Title XX was funded prior to conversion to a block grant.

Services provided through the SSBG to low income older persons are extremely important in allowing them to remain independent for as long as possible. Among these vital services are homemaker/home chore, adult day care, transportation, and home delivered meals. Without these services, older persons are far more vulnerable to premature institutionalization.

Continued federal support of social services for low income persons is critical, especially as cost-of-living protection in basic income security programs erodes. Other sources of social service funding are drying up; for example, a recent study by the National League of Cities showed that nearly half of the cities surveyed cut spending for social services last year to help balance their budgets. The SSBG should be fully funded in FY 1985.

CONCLUSION

The AARP is mindful of the continuing pressures generated by unacceptably large federal budget deficits. Consequently, despite the need for a significant expansion of services in many of the foregoing programs, we have for the most part asked for only modest increases in appropriations. We do, however, believe that some improvement in funding is justified even under the present difficult circumstances, and we urge the Subcommittee to adopt our recommendations.

Mr. AFFELDT. Thank you very much, Senator Inouye. At the outset, we want to commend you and also the subcommittee for your past support of the elderly. You have responded fairly compassionately and in a fiscally responsible manner.

AARP has six proposals which are covered in our longer statement. I shall summarize that statement and concentrate basically on three proposals.

First, AARP supports a $2.15 million supplemental increase for the SEP. This increase is needed now because, as you know, there will be a reduction in the number of temporary employees or positions without a supplemental appropriation.

Title V is currently funded at $319.45 million for the 1983–84 program year. Title V is, in effect, forward funded by 9 months. The fiscal year title V runs from July 1, in the case of 1983, to June 30, 1984.

Currently title V is funded to $317.3 million for fiscal year 1984, which is the full amount of the authorization; and fiscal year 1984 will begin on July 1, 1984, for title V.

We have good reason to believe that the Older Americans Act reauthorization bill will include an authorized funding level of $319.45 million for, title V and this will pave the way for a $2.15 million supplemental increase for the program.

Second, AARP supports full funding for title V for fiscal year 1985. As Mr. Simmons indicated previously, we do not know precisely what that amount will be because both the House and Senate reauthorizing subcommittees are working on that legislation now.

We expect that there will be a bill sent to the President in late spring, probably around May or June, and at that time we would know exactly what the authorized funding level would be; but, in any event, we urge the subcommittee to support the full amount.

Title V now has 62,500 authorized positions; however, the need is much greater for essentially three reasons. One, unemployment still remains high by historical standards for older Americans.

This does not take into account the discouraged workers and the hidden unemployed of which there are many among those persons 55 and older. Second, poverty is on the rise for persons 55 and older, especially those 55 to 64 years of age. Many of these individuals have become unemployed and exhausted their unemployment benefits.

Third, large numbers of older Americans are ready, willing, and able to serve in their communities if given the opportunity. This has been brought home in many projects that are conducted through the country.

The third proposal I'll cover in my oral testimony is title IV. We also recommend a $26 million appropriation for title IV, research, training, and demonstrations, under the Older Americans Act. This is $3.8 million above the existing amount and we recommend that this additional funding be used to bolster the following activities:

The Long-Term Care Gerontology Centers Program should have at least one center in each of the 10 HHS regions; the National Legal Services Demonstration Program should be expanded to provide more innovative approaches to delivering legal services to the elderly; and the Career Preparation Training Program should be expanded to enable more persons to work in the field of aging, especially minorities. This is one of the critical problems in the field of aging. There is a serious gap of adequately trained personnel.

Finally, demonstrations should be increased, particularly projects to assure more equitable treatment for older minorities, to assist the rural aged and to provide services for those afflicted with Alzheimer's disease.

We, too, are opposed to the administration's $5 million funding level for title IV. This is $17.2 million below the current appropriation. Title IV has already been cut by 55 percent since fiscal year 1980 from $54.3 million to $22.3 million.

AARP is mindful of the continuing pressures generated by our exceptionally large budget. Consequently in most of the foregoing programs we have asked for only modest increases in the foregoing programs. We do, however, believe that some improvement in funding is justified even under the present difficulty circumstances, and we urge the subcommittee to adopt these recommendations.

Senator INOUYE. I thank you very much.

Our next witness is Ms. Ruth E. Kobell, the legislative assistant for the National Farmers' Union.

STATEMENT OF RUTH E. KOBELL, LEGISLATIVE ASSISTANT, NATIONAL FARMERS' UNION

PREPARED STATEMENT

Ms. KOBELL. Good morning, Senator. We appreciate the opportunity to present testimony in support of appropriations for the Older Americans Act and I would like to associate myself with recommendations made by the two previous witnesses. We work closely together in a number of programs, including the program of the Senior Community Service Employment Program.

In light of the pressures of your time this morning, I would like to summarize my statement hoping that the full statement can be put in the record.

Senator INOUYE. It will be made part of the record at this time.

[The statement follows:]

STATEMENT OF RUTH E. KOBELL

I am Ruth E. Kobell, Legislative Assistant, National Farmers Union, Washington, D.C. We appreciate this opportunity to present our views in support of appropriations for the programs authorized under the Older Americans Act for the 1985 fiscal year. We understand that you are working on appropriations at the same time both Houses of Congress are considering reauthorization of the Older Americans Act so we are not able to speak to specific authorized funding levels.

This legislation now includes some programs that predate the original OAA enactment in 1965. The concept received strong support at the first White House Conference on Aging in 1961 and has provided authorization for the Conferences in 1971 and 1981.

The Older Americans Act provides a variety of incentives to keep older citizens healthy, independent and active in their communities. It provides structure and support for the senior nutrition programs, both congregate and home delivered meals which have proved so important to those who are served but which are able to reach only about one-third of the people who need them. We urge continued expansion of resources targeted to older individuals at nutritional risk. Separate funding is needed for the nutrition services and supportive services so that the emphasis won't be diminished in competition with other needs.

Surplus commodites administered by the U.S. Department of Agriculture provide $116 million in FY 1984 for senior nutrition programs which expands their resources and provides targeted assistance to hard pressed producers who are faced with depressed prices for commodities in temporary oversupply. This is a useful tool in the continuing effort to target our food abundance to those who need it. The system provides reimbursement on the basis of the meals served. This offers an incentive for nutrition programs to leverage funds to qualify for additional reimbursement and thus increase the number of meals which can be served. We oppose cashing out this program which would lose the impact of targeting support for particular commodities.

Title III of the Act provides for grants for state and community programs on aging and assigns to state and local aging offices the responsibility for planning, coordinating and administering programs as well as leveraging additional funds to expand available resources. In a short decade this network has reached into cities and towns across our nation and increasing support made that expansion possible, although there has been considerable cut in funds over the last three years. As resources become more limited, we believe it will be important that support be targeted with special attention to rural and minority needs.

The rapid growth in the number of citizens in the United States has reached the point where there are more people over 60 years than those under 16 years of age. This shift in the age of our population has necessitated the development of education, training, research and demonstration programs to provide both the information base and trained personnel to support aging programs.

Title IV was enacted to help meet these needs but funding has been cut in half in the last three years. It is now about equal to 1975 funding, although there has been a 95 percent increase in inflation from 1975 to 1983. We urge that funding cuts be restored. We hope the Administration on Aging will endeavor to improve distribution of research information to both Congress and advocacy organizations. We urge increased research on employment and other opportunities to help older Americans stay in the mainstream of their community life.

Grants for Indian tribes to deliver services to their older members are particularly important since these older women and men are often isolated from the larger community and most often have special needs for support and outreach.

While we have interest in all the programs under the Older Americans Act we have special concern for the resources provided to Title V, the Senior Community Service Employment Program under which Green Thumb operates. National Farmers Union is proud of our sponsorship of this employment program for older, economically disadvantaged women and men to deliver needed services to their rural communities and supplement their limited income.

Green Thumb, the first federally funded employment program for older workers, came into being with a grant from the Office of Economic Opportunity in 1965. The 1960 Census showed one-and-a-half million farm families, 14 million persons living in poverty in rural America. The Farmers Union sponsored the National Policy Committee on Pockets of Poverty, supported by the Twentieth Century Fund, which identified the need to stimulate concern and develop interest in a national movement to end poverty. We recognized that many of these farm families had fallen into poverty through forces beyond their individual control, through the rapid mechanization of agriculture and shifting of economic opportunities from rural communities to urban industrial centers. Older rural people did not have the mobility or resources to follow to new jobs.

The hallmark established by this program of using the skills, experience and commitment of older workers to fill unmet needs in their communities spurred the rapid growth of the older worker program over the last two decades. The Senior Community Service Employment Program demonstrates the ability and the need of older citizens to stay in the mainstream of their community and national life but it targets the limited resources available to those most in need of employment and income.

With the strong and continuing bipartisan support of Congress, Green Thumb has grown from 280 job opportunities in 4 states to 16,000 jobs serving 9,000 local sponsors in rural communities in 45 states and Puerto Rico. Although Title V is able to provide employment opportunities for only about 1 percent of those who are eligible, we believe it continues to demonstrate the use of this valuable and often untapped resource of our unemployed older people.

Last year Congress appropriated a total of $319.45 million in FY 1983 funds to provide 62,500 job opportunities for the program from July 1, 1983 to June 30, 1984. This exceeded the FY 1983 Title V authorization of $296.5 million. You secured a waiver to include $37.5 million in the Emergency Jobs law (Public Law 98-8) last year allowing 7,500 additional older women and men the opportunity to work.

Green Thumb and other program sponsors were able to immediately put these women and men to work on July 1, 1983 when the additional funds were made available as part of the new grant year because we had a skilled and experienced staff who knew that the money would be available as part of an emergency jobs effort and had both the applicants waiting for the opportunity to work and the community agencies asking for help with unmet community services.

The FY 1984 Labor-HHS Appropriations provide $317.3 million for Title V, the amount authorized under existing law. We understand that there has been discussion by the Subcommittee on Aging of the Senate Committee on Labor and Human Resources, chaired by Senator Grassley, to recommend an increase of $2.15 million in the FY 1984 authorization to meet the present funding levels. We urge you to provide the additional $2.15 million in your appropriations so the senior worker program can continue their present number of workers when the new grant year begins on July 1, 1984.

Although unemployment figures have shown a slow decline in the last several months, older workers continue to suffer a higher rate of unemployment for longer periods of time. The Job Training Partnership Act mandates that 3 percent of state funds be allocated to serve older workers, but a March 29, 1984 article in the Washington Post noted that "Training programs being set up under the JTPA seem to be focusing far more on meeting the needs of employers who have jobs to fill and less on reaching the young unemployed people most in need of training, according to a survey sponsored by the Rockefeller Foundation, the Ford Foundation and other groups."

We hope the record of targeted assistance for younger, older and other disadvantaged workers improves as JTPA gains experience. I want to make the point that SCSEP is the major effort by the federal government to provide help to older low income workers in finding employment, training and placement in public service or private full or part-time jobs.

Green Thumb has worked hard to assist over 17 percent of their workers to move into unsubsidized employment last year. While we recognize that many of our workers have little chance to find jobs in their rural communities outside of SCSEP, our staff continues to work with local employers to place an increasing number of older men and women in private employment. I wish we had the time to recount some of the exciting examples of these transitions.

A number of our state Green Thumb programs have used up to 3 percent of their grant funds under Sec. 502 of the 1981 Act to organize, recruit for and administer special experimental training and placement programs for SCSEP eligible workers. These have included training in home health care, high tech assembly, word processing, credit union accounting, nursing home jobs and factory assembly. This has included both classroom and work experience. Placement rates into often full-time better paying jobs is encouraging. We would be happy to brief you or your staff on these projects in more detail.

In our testimony supporting reauthorization of the Older Americans Act to the Senate Subcommittee on Aging on March 13, 1984 said: "We urge you to increase and target authorization levels to provide for increased costs and continuing growth in recognition of the needs of both communities and older workers. We believe that levels of $340 million for FY 1985, $370 million for FY 1986 and $400 million for FY 1987 would be targets reflecting past Congressional support."

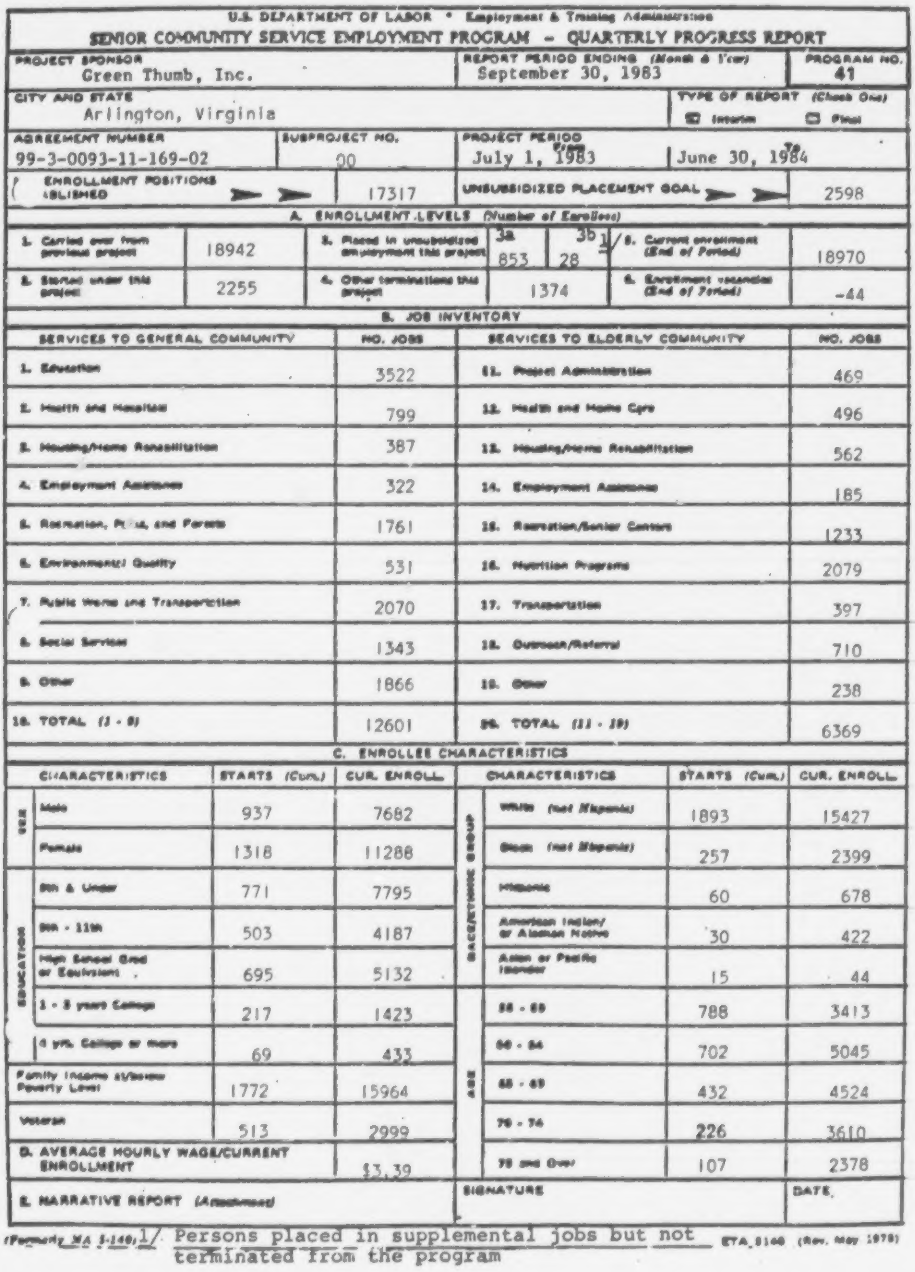
As I pointed out in the beginning of my statement, authorization levels for FY 1985 are not yet enacted into law but we urge your support for an increase in appropriations in recognition of increased operating costs and continuing need for employment opportunities for older workers. The Department of Labor still allocates $5,111 per enrollee which is the same funding level and average per enrollee cost that applied for the 1981-1982 program year although social security payroll taxes, workman's compensation and other operating costs continue to increase.

We recognize the high budget deficits with which Congress is wrestling. While tax policies, increases in military spending and high interest rates have imposed heavy pressures on the budget, high unemployment has pushed the number of citizens in poverty to a 17-year high. Rudolph Penner, the new head of the Congressional Budget Office, recently explained that since 1978 the rate of poverty for those under 65 effectively caught up with the rate for the elderly, which has remained about 15 percent since the mid-1970s.

A major new study on poverty challenges the notion that government programs create a long-term dependency by those in poverty. The 15-year study by the University of Michigan Institute for Social Research titled "Years of Poverty, Years of Plenty", concludes that people, for the most part, move in and out of poverty and that given time and opportunity to adjust, they will recover from poverty and will once again be paying taxes to support the very programs that aided them. They point out that about 2 percent of those who experience poverty remain persistently poor. A large number of this group are old or disabled and living in rural areas.

We believe the experience of Green Thumb which serves this targeted group has demonstrated that when poor, old people are given the opportunity to work themselves out of poverty, they are anxious, willing and able to do so. We urge you to continue to provide them with that opportunity.

Thank you.



U.S. DEPARTMENT OF LABOR • Employment & Training Administration

SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM – QUARTERLY PROGRESS REPORT

PROJECT SPONSOR Green Thumb, Inc.	REPORT PERIOD ENDING (Month & Year) September 30, 1983	PROGRAM NO. 41
CITY AND STATE Arlington, Virginia	TYPE OF REPORT (Check One) ☒ Interim ☐ Final	

AGREEMENT NUMBER 99-3-0093-11-169-02	SUBPROJECT NO. 00	PROJECT PERIOD From July 1, 1983	To June 30, 1984
ENROLLMENT POSITIONS ESTABLISHED	17317	UNSUBSIDIZED PLACEMENT GOAL	2598

A. ENROLLMENT LEVELS (Number of Enrollees)

1. Carried over from previous project	18942	3. Placed in unsubsidized employment this project	3a 853	3b 1/ 28	5. Current enrollment (End of Period)	18970
2. Started under this project	2255	4. Other terminations this project	1374		6. Enrollment vacancies (End of Period)	-44

B. JOB INVENTORY

SERVICES TO GENERAL COMMUNITY	NO. JOBS	SERVICES TO ELDERLY COMMUNITY	NO. JOBS
1. Education	3522	11. Project Administration	469
2. Health and Hospitals	799	12. Health and Home Care	496
3. Housing/Home Rehabilitation	387	13. Housing/Home Rehabilitation	562
4. Employment Assistance	322	14. Employment Assistance	185
5. Recreation, Parks, and Forests	1761	15. Recreation/Senior Centers	1233
6. Environmental Quality	531	16. Nutrition Programs	2079
7. Public Works and Transportation	2070	17. Transportation	397
8. Social Services	1343	18. Outreach/Referral	710
9. Other	1866	19. Other	238
10. TOTAL (1 - 9)	12601	20. TOTAL (11 - 19)	6369

C. ENROLLEE CHARACTERISTICS

	CHARACTERISTICS	STARTS (Cum.)	CUR. ENROLL.		CHARACTERISTICS	STARTS (Cum.)	CUR. ENROLL.
SEX	Male	937	7682	RACE/ETHNIC GROUP	White (not Hispanic)	1893	15427
	Female	1318	11288		Black (not Hispanic)	257	2399
EDUCATION	8th & Under	771	7795		Hispanic	60	678
	9th - 11th	503	4187		American Indian/ or Alaskan Native	30	422
	High School Grad or Equivalent	695	5132		Asian or Pacific Islander	15	44
	1 - 3 years College	217	1423	AGE	55 - 59	788	3413
	4 yrs. College or more	69	433		60 - 64	702	5045
Family Income at/below Poverty Level		1772	15964		65 - 69	432	4524
Veteran		513	2999		70 - 74	226	3610
D. AVERAGE HOURLY WAGE/CURRENT ENROLLMENT			$3.39		75 and Over	107	2378

E. NARRATIVE REPORT (Attachment)	SIGNATURE	DATE

(Formerly MA 5-140) 1/ Persons placed in supplemental jobs but not terminated from the program ETA 5140 (Rev. May 1978)

Ms. KOBELL. We believe that the Older Americans Act provides a variety of incentives for older citizens to remain healthy, independent, and active in their communities. I don't want to detail the various sections of the Older Americans Act that provide those kinds of support because they have been reviewed before.

We do believe that the nutrition programs are particularly valuable and we, as a farm organization, an organization of family farmers, are interested in and supportive of the Commodity Distribution Program that not only provides surplus commodities to child nutrition programs, but also to senior nutrition programs.

The number of older people in the United States has grown rapidly so that, as I understand it, there are now more people over 60 years old than there are under 16. I think we have to be aware of this as we target resources both for supportive services and for research, and particularly for employment.

As you may know, National Farmers' Union sponsors the Green Thumb Program which is one of the participants in title V, the Senior Community Service Employment Program. When we first asked for funding for a small project in 1965 it was the first program targeted specifically at employment of older people; and with broad bipartisan support from Congress it has been part of a rapidly growing effort to provide additional opportunities at the same time that it targets those resources to economically disadvantaged people over 55 years of age; and, of course, there is no top age limit. We have had people up to 100 years old working to provide services to their community.

As has been pointed out last year, Congress increased the funding by $37½ million as part of the jobs effort and we were proud of the fact that because there was a lead time—that is you, I think you passed that bill in about April—and the title V administrators recognized they were going to get some more money, by July 1 those funds were able to immediately start flowing to those economically disadvantaged people who needed the work and we were able to put people on the job almost immediately, July 1, when the funds were released as part of the new grant.

This does relieve us this year because it exceeded our authorized level with the $2.15 million shortfall of funding and we do hope that that can be considered in the supplemental.

We would certainly urge an increase of funding recognizing the increase in costs of the program. We know that Social Security is going up. We know that workmen's compensation rates are going up.

The funds provided and allocated by the Department of Labor had not recognized any increased administrative costs in 1981; and those are points to be considered, but particularly the number of older people who are unemployed, who need the employment, has increased.

As we've had the pressures of high unemployment, the slight reduction in unemployment has not reflected in this age group, largely. Many of them have not been able to find a new job. Many of them, their old jobs have disappeared. So we think that it is a justified consideration.

One of the points I'd like to make is that as the program has grown, there have been new demands made. For instance, there has been an increased emphasis on placing title V workers in private employment.

Green thumb placed 17 percent of their workers last year and, in rural areas where we operate, that's not always easy. We spent part of the funds, as targeted, on the innovative training programs and established training programs, often for the first time, for older workers in such things as home health care, technology training, and accounting—placed a high percentage of those.

The recent study on poverty by the University of Michigan pointed out, I think very importantly to me, that people historically have not stayed in poverty endlessly. They move in and out of poverty.

So that the programs that support them at one time are supported by them later on. They pointed out that perhaps 2 percent are in long-term poverty and quite often those are older minority people in rural areas; but we think that title V demonstrates that even these older people, often in rural areas, will work themselves out of poverty if they have a chance to do so.

We appreciate the bipartisan support from Congress over the years that has helped this program grow and continue. Thank you very much.

Senator INOUYE. I feel certain that this subcommittee will be very supportive of the amendment.

Ms. KOBELL. Thank you very much.

Senator INOUYE. Thank you.

STATEMENT OF PATRICIA THOMAS, LEGISLATIVE LIAISON, REPRESENTING JAMES M. PIERCE, PRESIDENT, NATIONAL FEDERATION OF FEDERAL EMPLOYEES

Senator INOUYE. Our next witness is Mr. James M. Pierce, president of the National Federation of Federal Employees.

Are you Mr. Pierce?

Ms. THOMAS. No; I'm not. [Laughter.]

Senator INOUYE. I didn't think so.

Ms. THOMAS. Thank you, I think.

Mr. Pierce is unable to appear today. My name is Patricia Thomas and I'm the legislative liaison with the National Federation of Federal Employees.

Senator INOUYE. You're welcome.

Ms. THOMAS. I'll be presenting our statement in Mr. Pierce's place. If I may, I would like to summarize our testimony.

PREPARED STATEMENT

Senator INOUYE. Your statement is made part of the record.

Ms. THOMAS. Thank you very much.

[The statement follows:]

STATEMENT OF PATRICIA THOMAS

Mr. Chairman and Members of the Subcommittee: The National Federation of Federal Employees appreciates this opportunity to testify on Fiscal Year (FY) 1985 Appropriations for the Social Security Administration (SSA) and the Job Corps Centers. NFFE represents a large number of employees in both agencies and we are therefore concerned that the Subcommittee provides adequate funding for them.

The Social Security Administration performs an essential function by providing services to over 50 million citizens. The agency administers special benefits to disabled coal miners, Supplemental Security Income benefits, and assistance payments to families with dependent children. In addition, it administers some disability and health insurance activities. The National Commission of Social Security acknowledged the importance of such entitlements in a 1981 report. The publication, Social Security in America's Future, noted that social security has been an integral part of American society since 1930. It has helped to achieve an improved level of security for the population while preserving the incentive for a productive life. The SSA's mission in administering social security and the various assistance programs has likewise become an integral part of the American plan.

It is my hope that the appropriations finally approved by this Subcommittee will adequately reflect the essential nature of the SSA's responsibilities. Sufficient funding for personnel is of primary concern to us. Over the last two years, the agency has been subjected to frequent personnel freezes which have resulted in reduced staffing levels. This has caused slowdowns in some areas which adds to the agency's work backlog. Currently, many SSA offices are experiencing a lack of secretarial staff - some offices must function with only part-time secretaries. Lack of funding has also been cited as the reason why the SSA's labor-management relations staff cannot respond in a timely manner to employee needs. Quite often, the agency's management staff cannot even meet the time limits they agreed to in contracts with our SSA Locals.

The President's FY 1985 budget request includes a decrease of 661 full-time permanent positions from FY 1984 levels, and a decrease of 1252 positions from FY 1983 levels. Nevertheless, benefit claims must still be expedited and the changes mandated by the Social Security Amendments of 1983 must be implemented. NFFE hopes the Subcommittee will recognize that the SSA requires additional staff to ensure the prompt response to such needs and that it restores the agency's employment to 1983 levels.

I would also like to call your attention to another area of great concern to our members. SSA employees continue to face repeated threats from displaced benefit recipients who become incensed about the reductions made in entitlement programs. The agency's employees are unfairly associated with the Administration's attempts to limit benefit eligibility, and they subsequently become subjected to assault from these individuals. Not only have our members received threatening phone calls but they have also been physically confronted by irate individuals. While none of our members have been fired upon, several shooting incidents have been targeted at SSA workers. Unfortunately, the danger has not been alleviated and has only increased. NFFE has repeatedly called for greater security personnel and precautions for our members but the Agency has refused to comply citing a lack of funding to provide the essential security. To make matters worse, insufficient funding has even caused a decrease in security. Where some security personnel were available at SSA offices, they are no longer present - even in some high crime areas.

Two years ago in testimony before the Subcommittee, NFFE outlined the security problems that existed within SSA offices. We hope that the Subcommittee will address these problems in the FY 1985 Appropriations bill by providing additional protective and guard service for all SSA offices. Civil servants should be protected to the greatest degree from assault and harassment while performing government work. NFFE looks forward to seeing this right enforced.

Finally, we would like to briefly discuss the funding for the Department of Labor's Job Corps program. There are currently 105 Job Corps centers in operation from Hawaii to Puerto Rico; 75 are operated by private contractors and 30 are staffed by Federal employees. Begun in 1964 to help disadvantaged youth lead productive lives, the Job Corps Centers have achieved a success rate in the 80 to 90 percent range. This year, however, the President's FY 1985 budget request seeks to reduce the funding for these Centers. The Department of Labor assumed that the Job Corps could continue to operate successfully with an appropriation of $634 million. Yet the Department's budget request seeks only $600 million in FY 1985. The $34 million reduction would be achieved by contracting out the remaining Job Corps Centers to private contractors.

NFFE is adamantly opposed to such action. During this period of high unemployment, we should devote even greater resources to the Government's efforts to reduce the jobless rate. Contracting out the civilian Job Corps Centers will not only jeopardize the program but it could also cost the taxpayers more money in the long run. Cost overruns, lack of accountability and often poor quality are well-documented products of the contracting out process. NFFE urges the Subcommittee to ensure the continued success of the Job Corps program by restoring the $34 million needed to maintain the civilian centers.

Ms. THOMAS. We would like to testify today on the fiscal year 1985 appropriations for the Social Security Administration and the Job Corps centers. NFFE represents a large number of employees in both agencies and we are, therefore, concerned that the subcommittee provide adequate funding for them.

It is our hope that the appropriations finally approved by the subcommittee will adequately reflect the essential nature of the SSA's responsibilities. Sufficient funding for personnel is of primarily concern to us.

Over the last 2 years the agency has been subjected to frequent personnel freezes which have resulted in reduced staffing levels. This has caused slowdowns in some areas which adds to the agency's work backlog.

Currently many SSA offices are experiencing a lack of secretarial staff. Some offices must function without any part-time secretaries. Lack of funding has also been cited as a reason why the SSA's labor-management relations staff cannot always respond in a timely manner to employee needs.

Quite often, the agency's management staff cannot even meet the time limits they agreed to in contracts with our SSA locals.

The President's fiscal year 1985 budget request includes a decrease of 661 full-time permanent positions from fiscal year 1984 levels and a decrease of 1,252 positions from 1983 levels. Nevertheless benefit claims must still be expedited and the changes mandated by the Social Security Amendments of 1983 must be implemented.

NFFE hopes the subcommittee will recognize that the SSA requires additional staff to ensure the prompt response to such needs and that it restores the agency's employment level to 1983 levels. I would also like to call your attention to another area of great concern to our members.

SSA employees continue to face repeated threats from displaced benefit recipients who become incensed about the reductions made in entitlement programs. The agency's employees are unfairly associated with the administration's attempts to limit benefit eligibility and they subsequently face assault by these individuals.

Not only have our members received threatening phone calls, but they have also been physically confronted by irate individuals. While none of our members have been fired upon, several shooting incidents have been directed at SSA workers.

Unfortunately, the danger has not been alleviated. It has only increased. NFFE has repeatedly called for greater security personnel and precautions for our members, but the agency has refused to comply citing a lack of funding to provide the essential security.

To make matters worse, insufficient funding has even caused a decrease in security. Where some security personnel were available at SSA offices they are no longer present, even in some high crime areas.

Two years ago in testimony before the subcommittee NFFE outlined the security problems that existed within SSA offices. We hope the subcommittee will address the problems in the fiscal year 1985 appropriation bill by providing additional protective and guard services for all SSA offices.

Civil servants should be protected to the greatest degree from assault and harassment while performing Government work. NFFE looks forward to seeing this right enforced.

Finally, we would like to briefly discuss the funding for the Department of Labor's Job Corps Program. There are currently 105 Job Corps centers in operation. Seventy-five are operated by private contractors and 30 are staffed by Federal employees.

This year the President's 1985 budget request seeks to reduce the funding for these centers. The Department of Labor assumed that the Job Corps could continue to operate successfully with an appropriation of $634 million, yet the Department's budget request seeks only $600 million in fiscal year 1985.

The $34 million reduction would be achieved by contracting out the remaining Job Corps centers to private contractors. NFFE is adamantly opposed to such action.

During this period of high unemployment we should devote even greater resources to the Government's effort to reduce the jobless rate. Contracting out the civilian Job Corps centers will not only jeopardize the program, but could also cost the taxpayers more money in the long run.

Cost overruns, lack of accountability, and often poor quality are well documented products of the contracting out process. NFFE urges the subcommittee to assure the continued success of the Job Corps Program by restoring the $34 million needed to maintain the civilian centers.

That concludes my statement.

Senator INOUYE. I congratulate you. The green light is still on. [Laughter.]

I was quite curious about the security problem.

Ms. THOMAS. Yes.

Senator INOUYE. Is that widespread throughout the United States?

Ms. THOMAS. It is widespread. It's not particular to any region. We have a Social Security Administration Council of all our Social Security Administration locals and this is one of their major concerns.

It's something that has not appeared recently. It's something that is ongoing.

Senator INOUYE. All of us in the Congress are quite sensitive to this because we're constantly threatened, but our skins are thick.

Ms. THOMAS. So are Federal employees' skins.

Senator INOUYE. Well, we will look into this, I can assure.

Ms. THOMAS. Thank you very much.

Senator INOUYE. Thank you very much.

STATEMENT OF ARNOLD WACHACHA, JTPA DIRECTOR, EASTERN BAND OF CHEROKEE INDIANS

PREPARED STATEMENT

Senator INOUYE. Our next witness is the JTPA director of the Eastern Bank of Cherokee Indians, Mr. Arnold Wachacha. Mr. Wachacha, welcome, sir.

Mr. WACHACHA. Thank you.

Thank you for the opportunity to testify before the committee.

Senator INOUYE. Your full statement is made part of the record, sir.

Mr. WACHACHA. OK. Thank you.

[The statement follows:]

STATEMENT OF ARNOLD WACHACHA

Thank you for the opportunity to testify before the Committee concerning the Fiscal Year 1985 Department of Labor budget for employment and training programs serving Indian and Native American workers.

Special programs to serve our people are authorized as national programs under Title IV of the Job Training Partnership Act. A total of 194 Indian tribal governments, inter-tribal consortia, native Alaskan groups, off-reservation Indian organizations and one native Hawaiian group are currently funded under Title IV to provide employment and training services to Indian and Native American workers throughout the country. In addition, tribal governments, inter-tribal consortia, native Alaskan groups and the native Hawaiian grantee receive Summer Youth Employment and Training Program funds under Title II-B.

The President's FY 1985 budget request would continue the FY 84 funding level for Indian programs under both Title IV and the Summer Youth authorizations. Indian Title IV programs receive $62.2 million, while Indian Summer Youth activities receive $13.2 million.

While we have seen unemployment rise sharply in Indian communities, funding to meet our needs has fallen precipitiously, down to nearly the level it was ten years ago -- without any adjustment for inflation.

The only recent official figures on Indian unemployment come from an annual survey of reservation conditions made by the Bureau of Indian Affairs. The 1983 report shows that just over half -- 51% -- of the Indian reservation labor force is out of work. This is up from 46% the year before. Eleven reservation areas with populations over 500 were reported in 1983 to have unemployment rates of 80% or higher.

Resources to meet these staggering levels of joblessness have nearly vanished. The cut in Indian JTPA funds in FY 84 came on top of huge cuts over the previous several years. When Indian employment and training programs started ten years ago, $71.4 million was appropriated for them. The amount available as recently as January of 1981 was $182.6 million. Now, and under the President's request for next year, the amount available under all JTPA Titles totals $75.4 million.

The Indian and Native American Employment and Training Coalition has analyzed the funding cuts on Indian programs in states with major Indian reservation areas. The results are shown on the attached table, along with the official BIA-reported unemployment rates for the reservations in those states.

Is there any way this Committee can stop this hemorrhaging of the resources we need to build a decent economic future for Indian and Native American people?

COMPARISON OF FY 81 and FY 84 FUNDING LEVELS FOR INDIAN AND NATIVE AMERICAN PROGRAMS

State	FY 1984 Level Compared to FY 1981 Level	Unemployment Rate: BIA
Alaska	- 75%	62%
Arizona	- 66%	59%
Idaho	- 59%	66%
Minnesota	- 60%	65%
Montana	- 61%	56%
New Mexico	- 63%	47%
North Dakota	- 70%	63%
South Dakota	- 65%	74%

State	FY 1984 Level Compared to FY 1981 Level	Unemployment Rate: BIA
Washington	- 66%	63%
Wisconsin	- 62%	53%

Note: The funding level figures for FY 81 include amounts allocated to all Indian and Native American grantees in the states shown under all CETA Titles pursuant to the second continuing resolution for that Fiscal Year. The funding level figures for FY 84 are the annualized allocations to Indian and Native American grantees for the "Transition Period." The funding information was abstracted from DOL records by the Indian and Native American Employment and Training Coalition. The unemployment rate information was taken from the BIA Labor Force Survey released in August 1983.

In order to effectively use whatever employment and training program money is available, we also need proper administrative support from the Department of Labor. Congress tried to insure this support when it provided in Section 401(e) of JTPA:

> "The Secretary is directed to take appropriate action to establish administrative procedures and machinery (including personnel having particular competence in this field) for the selection, administration, monitoring, and evaluation of Native American employment and training programs authorized under this Act."

We haven't gotten that support, and our programs have suffered. There are several major problems.

First, we at the operating level waste a great deal of our scarce time and funds just figuring out who to talk to about our grants inside DOL's Employment and Training Administration. Currently we must deal with four separate ETA offices. The office we are supposed to work with -- the

Division of Indian and Native American Programs (DINAP) -- has virtually no authority and cannot sign off on a single grant action. In addition, we are now told that 10% of all Indian grants will be "monitored" by the debt collection office, an office that has no staff with any familiarity with the operation of Indian programs and no organizational connection to DINAP.

All this duplication must be costing the government money. Is there any way this Committee can put a stop to such waste?

Secondly, the law specifically requires that DOL administer Indian programs with staff that knows something about our programs. The only Indian people in DOL that deal with Indian JTPA programs are in DINAP. There are practically none left there, and the current RIF may wipe out all of them.

In the fall of 1981, there were 13 Indians on a DINAP staff of 30. Now there are 4 Indians on a DINAP staff of 25. DOL has done nothing to insure that any of them will be left in the Indian Division after the RIF.

Can this Committee do anything to force the Department to comply with the explicit mandate in the law?

One other issue related to the DOL budget is important to our programs. This is the funding of the audits of Indian JTPA grants.

Until recently, all DOL audits of Indian JTPA and CETA grants were paid for out of funds appropriated to DOL's Office of the Inspector General. Now, more and more Indian grantees are expected to pay for these audits out of their Title IV JTPA program funds. While Indian program funds have been cut drastically, there has been no reduction in the OIG's budget.

Indian tribal governments are covered by Attachment P to OMB Circular A-102. This Attachment requires covered organizations to implement -- at their own expense -- a single, organization-wide audit of all the federal funds they receive. The Attachment P process is now being implemented by more and more tribal governments. DOL is considering applying the concept to all Indian and Native American grantees.

Those tribal governments that have used it have found that an Attachment P-type audit is simpler, more efficient and much more useful in improving financial management practices. They strongly support the process, particularly in contrast to the punitive audit system DOL previously used to deal with the Indian program.

However, there is no money available to grantees to pay for this additional cost.

Can this Committee order the transfer of funds appropriated for DOL's Office of the Inspector General to Indian grantees for the specific purpose of paying the additional costs of Attachment P audits?

Thank you for this opportunity to discuss the implications of the FY 85 DOL budget on Indian and Native American employment and training programs.

LETTER FROM ARNOLD WACHACHA

April 11, 1984

The Hon. Daniel K. Inouye
Member
Subcommittee on Labor-HHS-Education
Committee on Appropriations
United States Senate
Washington, D. C. 20510

Dear Senator Inouye:

This is in response to the question you asked me at the hearing today about the seven different offices in the Department of Labor I must deal with regarding the DOL employment and training funding provided to the Eastern Band of Cherokees.

The first office is DINAP -- the Division of Indian and Native American Programs. This is supposed to be my contact point in DOL. However, this office does not have the authority to sign any final grant documents for any Indian or Native American grantees.

Section 401(e) of JTPA says that Labor must hire people with "particular competence" in Indian and Native American programs to administer our programs. There are only four Indian people left in DINAP out of a staff of 25. Several years ago there were 13. One-third of the current DINAP staff have come into that office in the last two years. None of them had any prior experience in Indian or Native American programs. We are now told that even though the RIF may leave DINAP with just about the same number of slots, all of the people now in those slots may be displaced bacause of bumping and other effects of the RIF. We may soon have no Indian people at all in the "Indian" Division. All of the non-Indian people there now that know about our programs may be gone, too.

The second office I have to deal with is Contracting. The person authorized to sign all current Indian grant actions is the Grant Officer in that office. The man who has that job is leaving, in part to avoid the chaos being caused by the RIF. He is the third Grant Officer we have had in the last two years. Every time the people there get to know a little about Indian programs, they leave or are reassigned.

The third office I have to deal with is audit resolution. This office handles the issuance of "findings and determinations" based on past audits. It tells us whether we supposedly owe DOL any money, but fortunately its decisions are subject to appeals to Administrative Law Judges.

The fourth office I have to deal with is debt collection. This is the office that forces us to pay any money DOL claims we owe because of disallowed costs on old audits. Its policy is to force us to pay all our "debts" to DOL in cash, something very hard for Indian tribes and organizations to do. We are now told that this same office will "monitor" or "review" at least 10% of Indian and Native American grants, even though it has no staff familiar with the operation of Indian programs. It has no connection with DINAP, which is supposed to be our main contact in DOL.

The other three offices are accounting, grant close-out and property.

I am not sure I know the exact names of all these seven offices. The names of the offices and the people in them seem to change all the time, and it is very hard to keep track of them. For example, I have had five DINAP project officers (Federal Representatives) assigned to my program at various times over the last year.

All Indian and Native American grantees, including the Native Hawaiian program operated in your state by Alu Like, have similar problems. In Alu Like's case, the organization's staff has to deal with all these different offices in Washington, D. C. since DOL ordered the closing of the DINAP offices in San Francisco and Seattle, despite the protests of grantees in the western United States.

I hope that you can help us straighten out this bureaucratic maze.

If you have any other questions or if we can furnish any other information, please contact me in Cherokee, N. C. at (704) 497-5601 or call Norm DeWeaver at the Indian and Native American Employment and Training Coalition in Washington, D.C. at 342-0594.

Thank you very much.

Sincerely,

Arnold Wachacha

Arnold Wachacha
JTPA Director
Eastern Band of
Cherokee Indians

Mr. WACHACHA. My name is Arnold Wachacha, JTPA director for the Eastern Bank of Cherokee Indians in western North Carolina. We have a reservation there of 54,000 acres. There are 600 tribal members there.

One of our biggest problems there is unemployment, like everybody else has been talking about this morning, but ours happens to be 54 percent unemployment.

Senator INOUYE. You mean throughout the Indian nations of the United States?

Mr. WACHACHA. Well, it's pretty close to that throughout Indian country all throughout the United States. I think this is a problem that I'd like the committee to really look at.

Of course, if you have unemployment, you know, we have other problems that arise from that. In our statement we do list the percentages of unemployment throughout the country.

Senator INOUYE. I will present your statement, also, to the Indian Affairs Committee. I'm a member of that committee and I don't believe the numbers were that high as presented to us, but I think it's very interesting.

Mr. WACHACHA. Well, you know, I think a lot of those statistics did come from BIA; but my ability to help the unemployed Indian of my reservation is limited because of money because we've had such a big cutback in the last 4, 5, 6 years; and even in the last year it's been drastic.

I used to be able to serve 180 adults and 100 in-school kids. I'm down to where I serve 40 people now, 40 adults, and 50 youth. That's pretty much a big cut I'd say.

Now, we need more jobs to help our people on the reservation and, like I said earlier, that is true all across Indian country. We're naturally trying to establish industry to come into our reservation, but you know it's hard without money and without proper training. It's very difficult.

But we have started to make progress in this area. We've established a strong GED Program on our reservation. About 75 percent of the participants that graduate through our GED Program go on to get jobs.

It has also been very effective through their kids. They're making their kids go to school by showing them the importance of having a GED Program.

Just recently, we had a cable TV repair company come to our reservation who was going to hire 125 people. Right away, the first thing that they said, they had to have a high school education or a GED.

Through the years where we had established the good GED Program we were ready for it; but they still had to go to school at night on their own in order to get these jobs. Our people are motivated and they're doing that right now.

Our prepared statement also mentions, here again, that we need funding; but I would like this committee to know that we have an office that we're supposed to deal with, which is DINEP, Division of Indian Educational Programs, but they seem like they have no authority to tell us anything.

I have to deal with seven different agencies for one grant and the Indian Division that is established really can't tell me anything. They can't sign the grants. They have to go to these other departments.

Senator INOUYE. Who signs the grant eventually? Somebody has to sign it——

Mr. WACHACHA. Yes.

Senator INOUYE [continuing]. But what agency signs it?

Mr. WACHACHA. The contracting officer. With these seven different agencies, you know, they all have different authority, and they're directly affecting our grants. I think they need to come up with one program that we can deal with, one department, which is DINEP naturally, that's designed for the Indians.

At this point, they seem like they don't have any authority. Like I said, they can't sign any documents.

The JTPA also is required to by law to staff people that know something about the Indian programs, which is not being done at this time.

Senator INOUYE. It's not being done?

Mr. WACHACHA. We have four Indians in the program right now that know a little something about the JTP Program. With the RIF that's come down, we've got so many new people in different agencies that are in that program right now, it's ridiculous.

In fact, the program people out in the field know more about the JTP Program than the people that are supposed to be telling us, but this is all because of the RIF. I think, you know, we need to stabilize.

Senator INOUYE. OK.

Well, I can assure you, Mr. Wachacha, that this committee is very sensitive to these unique problems of the native Americans, the American Indians, and we'll do everything we can to help alleviate some of your problems, especially your bureaucratic maze that you have to go through of seven agencies. I think that's uncalled for.

Mr. WACHACHA. Yes, it is.

Senator INOUYE. We'll do something about that.

If you could provide us with an addendum memo telling us what these agencies are, we'll get together with all of them——

Mr. WACHACHA. OK. I can do that.

Senator INOUYE [continuing]. And straighten out the bureaucratic maze. Bureaucrats like to do that. All seven feel very important.

Mr. WACHACHA. Yes, they do; and they directly affect us.

Senator INOUYE. Thank you very much.

Mr. WACHACHA. Thank you.

STATEMENT OF NATHAN MEGIDA, CHAIRMAN, BRIDGEPORT, CT, PRIVATE INDUSTRY COUNCIL REPRESENTING DAVID COLE, DIRECTOR OF DATA PROCESSING, TRAVELERS INSURANCE CO.

PREPARED STATEMENT

Senator INOUYE. Our next witness is the director of the Travelers Insurance Co., Mr. Frank Cole.

Mr. MEGIDA. Senator, I'll be substituting for Mr. Cole who is not able to be here. I would request that the memo that I sent to Ms. Falsey be amended to show that I am the incoming chairman of the Bridgeport, CT, Private Industry Council. We're a regional organization and kind of a pioneer, in that sense.

The statement that was submitted by Frank Cole is pretty representative of my views on the activities on the joint training partnership.

Senator INOUYE. At this time, Mr. Frank Cole's statement will be made a part of the record.

[The statement follows:]

STATEMENT OF FRANK COLE

My name is Frank Cole. I am the director of data processing for the Travelers Insurance Company in Hartford, Connecticut. I was formerly the director of the Hartford Comprenhensive Employment and Training Program. Now, in addition to my duties with the company, I serve with on Connecticut's State Job Training Coordinating Council. This morning I wish to make just a few points: training is an investment that pays off; private sector involvement is making it even better; the combination of the strength of the New England economy and the demographics of the next ten years show that we need more financial resources for the program. I appeal to the Senate Appropriations Committee to maintain a current services level for training programs rather than cutting the program back.

Training as an Investment

Careful studies show that training, including training under the CETA Program, was cost effective for people in the program and for the taxpayers who payed the cost. On-the-job training, for instance, led to wage gains of $839 over those of control groups. People in classroom training gained nearly $350. Since the average investment was only about $4000, and these wage gains are likely to continue for some years, it is clear that investment in training makes sense.

Long-term training is especially valuable. Those who are in programs lasting forty weeks or more gained $1,377 more in annual earnings than those in a control group. Finally, the studies show that the people who may be in the worst shape, women on welfare, tended to gain the most from the training programs.

The Job Training Partnership Act in Connecticut

Under the JTPA, private industry councils (PICs) have been established throughout Connecticut. Speaking as a businessman who has worked both with the CETA Program and the new legislation, I believe that the private sector participation through PICs is adding a critically important new dimension. Job training for the disadvantaged must be first quality training and graduates must have access to private sector jobs. Businessmen and women who serve on the PIC can see to it that the training is relevant to private sector needs and they can help organize access to private sector jobs with major employees. They can also insist that bureaucratic paperwork be kept to an absolute minimum.

Economic Growth and the Demographics of the 1990s

Connecticut's economy is strong and expected to be stronger however the demographics show that by the early 1990s there will be a 20% decline in the 16-24 year old age group. If Connecticut's expanding industries are to find qualified entry-level workers, then the job preparation made available to disadvantaged citizens, Blacks, Whites, and Hispanics, men and women, must imporve in quality and scale. Now is the time to build the institutional infrastructure that will make it possible for us to provide opportunity to all our citizens and to provide trained workers for our economy over the next ten years.

Funding

In Connecticut money is so tight now, and the decline of available training dollars has been so substantial over the last few years, that there is pressure to concentrate on very short-term interventions, such as immediate placement activity rather than investment in the long-term training programs which are more expensive but which pay the greatest returns on investment. The Administration in its budget proposes to cut back by eliminating $271 million from the WIN Program and $87 million from the Summer Jobs Program and to level fund the Block Grant despite continuing inflation. I want to ask this Committee to seriously consider providing enough money to continue the training programs at a current services level.

Thank you, Mr. Chairman.

Mr. MEGIDA. I don't intend to repeat it. I would like to make a couple of comments to amplify and explain my own position.

I am grateful for the opportunity to talk to you today. I think fundamentally the joint training project is working. I think it is fundamentally sound. We perceived in the very early stages a major problem, particularly that of stipends for participants and clients. I realize that that is an authorization matter rather than an appropriation matter, but it is or was a significant factor. And we are not so sure anymore, it might not be as bad as we thought it was. And I don't want to overemphasize. It should be looked at, we should continue to look at the function of stipends and the Training Program.

We haven't heard from the business community on this program. Perhaps we are too busy getting going. We are getting used to the idea that the business community really has primary control over the activities of this program. We are getting organized to exercise that control, and we are beginning to build a structure to maximize the efficiency with which business can impact the program in the future.

Our efforts are particularly aided by the apparent intent of Congress when the bill was passed to make this a continuing program, and we are further encouraged by the fact that we are already funded through June 1985. The appropriations bill that you are considering now will pick up our program starting then.

This continuing—this continuing new program has given us some time to build a sense of involvement on the part of the business community. We are beginning to see successes. We are beginning to overcome some of the skepticism that existed in the early stages when business people really didn't believe that they were going to have a shot at controlling this program.

I see in my own experience a much greater level of enthusiasm, a much greater sense of having a meaning, having some long-term impact on the serious problem of training people. I think it is extremely important that this continuity be maintained. That the appropriations function continue activities under the Joint Training Partnership Act at a reasonble level. The level that we are conducting now, adjusted for inflation, so that we in the business community see that this is a national commitment, that we can continue to put our efforts into the program and that we know that what we are doing now is not just being dumped down a big tube.

I would appreciate your efforts in that direction. After all, success builds on success.

We are having successes in our service delivery areas. We are placing people in good jobs and our cost per placement is really quite good. I would like to see it continue.

I don't want to go much further, sir. It is my intent to answer some questions, if you have them. There are a couple of other points that I might make after answering your questions.

Senator INOUYE. You just heard Mr. Wachacha. Do you have any problem with bureaucracy also?

Mr. MEGIDA. We are not terribly involved with that. It is my sense that in Connecticut things are running fairly smoothly. I do have some problems.

Some of our service providers have had some serious problems with paperwork. The school systems particularly are discouraged by the amount of paperwork that is required. We sense that this paperwork is, in large manner, part of the detailed audit that is required after the poor experiences with prior legislation.

We don't seems to run into that level of problem. The State Department of Labor in Connecticut is quite competent and seems to do the job rather well.

Senator INOUYE. What type of clients do you handle?

Mr. MEGIDA. We cover the area from Greenwich——

Senator INOUYE. The chairman is from Connecticut.

Mr. MEGIDA. Yes; I know. We cover the area from Greenwich to Bridgeport, I guess about 30 miles, and north up the river valley, it's a pretty heterogeneous area in that it comes from the most affluent communities in the region to Bridgeport which is not a particularly happy place economically.

The clients are very disadvantaged in the western part of the State of the region in Greenwich and Stamford. These are the people who are there but are really marginally employable at this point if employable at all. We go a little further east toward Bridgeport and we tend to get into people who are laid off from the older machine tool trade in the region and need retraining to become eligible for the more modern jobs that are moving into the area. It's a wide ranging set of clients.

Senator INOUYE. Quite a challenge there.

Mr. MEGIDA. Oh; yes, indeed, but I think it has worked.

Senator INOUYE. How about your fishing industry?

Mr. MEGIDA. Not in our part of the States. It's all sports fishing down there.

Senator INOUYE. Well, I thank you very much, Mr. Megida. You have been most helpful, sir.

Mr. MEGIDA. Thank you for the opportunity.

STATEMENT OF PEGGY TAYLOR, LEGISLATIVE REPRESENTATIVE, AMERICAN FEDERATION OF LABOR AND CONGRESS OF INDUSTRIAL ORGANIZATIONS [AFL–CIO]

PREPARED STATEMENT

Senator INOUYE. Our next witness is Ms. Peggy Taylor, legislative representative of the AFL–CIO. Welcome.

Ms. TAYLOR. Thank you.

Senator INOUYE. You have been waiting a long time.

Before you start, I will tell you that your full statement will be made a part of the record at this time.

[The statement follows:]

STATEMENT OF PEGGY TAYLOR

The AFL-CIO appreciates the opportunity to testify before this Subcommittee on the policies and activities of the Department of Labor as expressed through their FY 1985 budget request. In the limited time available, our review cannot be comprehensive but will be illustrative of the activities of this Labor Department which cause us grave concern for working men and women.

Our concerns can be broken down roughly into four areas:

1) Our overriding concern is the severe reduction in resources available for labor standards enforcement and job training services for working men and women.
2) We feel that, through its regulatory activities and its resource misallocation, the Labor Department has shown a strong bias against the workers and their institutions and has become, instead, the protector of the employer.
3) We believe staff of the Labor Department have been demoralized by a series of firings and firing threats, wholesale downgradings, and consequent reassignment of staff to duties which mismatch their experience and interest.
4) And, finally, it is our assessment that the political appointments at the Labor Department bespeak the Administration's low regard for the function of this agency by virtue of either a lack of relevant experience or an outright hostility to the purposes of the agency.

I. Resource reduction and misallocation

The staffing levels for the Department of Labor requested in the FY 1985 budget are at a level which is 21 percent below the authorized staffing level in FY 1980. Within that overall reduction, even greater reductions are occurring in those areas of the Department which administer manpower training programs or enforce labor standard laws as shown below:

DOL OFFICE	Percentage change in authorized positions FY 1980 to FY 1984
Employment & Training Admin. (all job training & employment programs)	-49%
Occupational Safety & Health Admin.	-23%
Mine Safety & Health Admin.	-19%
Employment Standards Admin. (enforcement of minimum wage, child labor standards, Davis-Bacon, Service Contracts Act, et. al.)	-22%
Labor-Management Services Admin. (exclusive of new investigative staff granted or requested FY '83-FY '85)	-27%

The only significant staff increases requested by the Department of Labor during this time has been for criminal investigators and auditors to look into labor union activities.

Many of these staffing reductions the Department has justified on the grounds of greater program efficiency and staff productivity. But a look at what has happened in OSHA, as a case study, invalidates that argument. For example, OSHA'S increased enforcement productivity is the statistical result of exemptions from inspections for whole categories of industries and the substitution of paperwork inspections for actual workplace inspections. I will submit more about this later.

2. Bias against workers and their institutions

Not only has this Labor Department done little that could be described as furthering the health and welfare of the American workers or the unemployed, but the AFL-CIO would categorize numerous of the Department's actions as setbacks for workers.

Within the Occupational Safety and Health Administration, in three years the agency has issued only one new final health standard -- a standard which we find inadequate. But in that same time period six final actions have been taken to revoke, weaken or suspend existing health standards.

Although OSHA is using records inspections for one-fifth of total inspections, it has declined to fund any effort to evaluate and improve the quality and accuracy of these records, which were not set up for such a priority function.

In the wage standard area, the Department reversed a 40-year history under Democratic and Republican Administrations of consistent enforcement of the Davis-Bacon Act wage protections and gutted the effect of that legislation by regulatory action. A similarly destructive regulatory change was made in administration of the Services Contracts Act.

Recent House Labor-Management Relations Subcommittee hearings have documented the virtual abandonment of enforcement of the Labor and Management Reporting and Disclosure Act provisions related to activities of employers and their labor-management consultants, despite an enormous increase in these activities and overwhelming evidence of violation of these provisions. In March 1982 when the Labor Management Services Administration instructed its field offices to process only those employer and consultant cases based on complaints, scores of cases were closed where violations of the law had already been documented. Yet additional staff are being requested by LMSA to increase enforcement of other provisions the same Act with regard to unions despite lack of evidence of violation.

Particularly egregious to us is the resource misallocation represented by the concurrent degradation of enforcement of the labor safety, health and wage standard laws at the same time that the Department is shifting resources to the investigation of labor union leadership, finances and operations.

3. Demoralization of DOL staff

For three years this Administration has been driving talented people out of government by a combination of disdain for their work, disavowal of the purpose of the programs they have dedicated themselves to, attacks on their retirement programs and, directly and personally, firings, downgradings and reassignments to tasks unrelated to individual's talents, experience or interest.

The Labor Department heirarchy, in its gleeful, anorexic embrace of this Administration's attitude toward its workers, has been planning to get the jump on its FY 1985 staffing reduction proposals by RIFing in FY 1984 sufficient personnel to attain an end-of-year employment level in the Employment and Training Administration roughly 250 positions below its authorized FY 1984 level. This unilateral action would deprive the employees and the constituent groups of the Department of any opportunity for a hearing before the Congress on this action prior to its accomplishment.

Almost as destructive as the loss of staff through heavy attrition and reductions in force, is the wholesale downgradings planned where personnel may be reassigned to jobs two or three grades below their previous job level.

4. Quality of staff appointments

During the past four years the political appointments at the Department of Labor from the Secretary through his Assistant Secretaries and their closest advisors predominently have come from the business community - as company presidents, vice presidents or corporate management lawyers and -- even from the employer-financed anti-union National Right-To-Work Committee. With one brief exception, for perhaps the first time this century there has been no serious interest in bringing into the Labor Department persons at high levels who represent the workers' point of view. Without casting aspersions--at this point-- on the character of the individual political appointees of the Labor Department, we believe that caution should be exercised in evaluating the program judgments of these people whose natural constituency is not the worker, the unemployed or the poor.

Actions Requested of the Appropriations Committee

We realize that this Subcommittee will be operating within constraints that do not allow the large program increases that we would ideally like to see in Labor Department programs. We would, however, recommend the following:

1) Any staffing increases granted be for the purpose of labor standards enforcement or job training activities.
2) That agencies of the Labor Department be instructed to allocate their resources so that priority is given to protecting workers from hazards, discrimination and joblessness.
3) That DOL reductions-in-force and downgradings be stopped.
4) That the Committee look skeptically at the recommendations made to it by a Department which has shown no sympathy for its basic mission of protecting workers.

Ms. TAYLOR. The AFL–CIO appreciates the opportunity to testify before this subcommittee on the policies and activities of the Department of Labor as expressed in the fiscal year 1985 budget request. In the limited time available, our review cannot be comprehensive but will be illustrative of the activities of this Labor Department which causes us grave concern for working men and women.

Our concern can be broken down roughly into four areas:

Our overriding concern is the severe reduction in resources available for labor standards enforcement and job training services for working men and women.

We feel that, through its regulatory activities and the resource misallocation, the Labor Department has shown a strong bias against the workers and their institutions and has become, instead, the protector of the employer.

Third, we believe the staff of the Labor Department has been demoralized by a series of firings and firing threats, wholesale downgradings, and consequent reassignment of staff to duties which mismatch their experience and interest.

Senator INOUYE. Didn't you sent us a memo on that?

Ms. TAYLOR. Yes; and this goes into what Mr. Wachacha was talking about. Where people who were left were reassigned to jobs that they have no experience for, no competence for, and finally, it is our assessment that the political appointees at the Labor Department bespeak the administration's low regard for the function of this agency either by virtue of lack of relevant experience or by outright hostility to the purposes of the agency.

I'll address each of these very briefly.

Resource reduction misallocation. The staffing levels for the Department of Labor requested in fiscal year 1985 are at a level which is 21 percent below the authorized staffing level of fiscal year 1980. Within that overall reduction, even greater reductions are occurring in those areas of the Department which administer manpower training programs or enforce labor standard laws as shown.

The only significant staff increases requested by the Department of Labor during this time has been for criminal investigators and auditors to look into labor union activities.

Many of these staff reductions the Department has justified has been on the grounds of greater program efficiency and staff productivity. But a look at what has happened in OSHA, as a case study, invalidates that argument. For example, OSHA's increased enforcement productivity is the statistical result of exemptions from inspections for whole categories of industries and the substitution of paperwork inspections for actual workplace inspections. We intend to submit further on that.

Bias against workers and their institutions. Not only has this Labor Department done little that could be described as furthering the health and welfare of the American workers or the unemployed, but the AFL–CIO would categorize numerous of the Department's actions as setbacks for workers.

Within the Occupational Safety and Health Administration, in 3 years the agency has issued only one new final health standard—a standard which we find inadequate. But in that same period of time six final actions have been taken to revoke, weaken, or suspend existing health standards.

In the wage standard area, the Department reversed a 40-year history under Democratic and Republican administrations of consistent enforcement of the Davis-Bacon Act wage protections and gutted the effect of that legislation by regulatory action.

Recent House Labor-Management Relations Subcommittee hearings have documented the virtual abandonment of enforcement of the Labor and Management Reporting and Disclosure Act provisions related to activities of employers and their labor-management consultants, despite an enormous increase in these activities and overwhelming evidence of violation of these provisions.

Particularly egregious to us is the resource misallocation represented by the concurrent degradation of enforcement of the labor safety, health, and wage standard laws at the same time that the Department is shifting resources to the investigation of labor union leadership, finances, and operations.

Demoralization of DOL staff. For 3 years this administration has been driving talented people out of the Government by a combination of disdain for their work, disavowal of the purpose of the programs they have been dedicated to, attacks on the retirement programs and, directly and personally, firings, downgradings, and reassignments to tasks unrelated to individual's talents, experience or interest.

The Labor Department's hierarchy, in its gleeful, anorexic embrace of this administration's attitude toward its workers, has been planning to get the jump on its fiscal year 1985 staffing reduction proposals by RIFing in fiscal year 1984 sufficient personnel to attain an end-of-year employment level in the Employment and Training Administration roughly 250 positions below its authorized fiscal year 1984 level.

Almost as destructive as the staff losses through attrition and reduction in force, is the wholesale downgradings planned where personnel may be reassigned to jobs two or three grades below their previous—below their present job level.

Quality of staff appointments. During the past 4 years the political appointments at the Department of Labor from the Secretary through his Assistant Secretaries and their closest advisers predominantly have come from the business community—as company vice presidents or corporate lawyers—even from the employer-financed antiunion National Right-To-Work Committee. With one brief exception, for perhaps the first time this century there has been no serious interest in bringing into the Labor Department persons at high levels who represent the workers' point of view.

We would recommend to the subcommittee the following: That any staffing increases be granted for the purposes of labor standards enforcement or job training activities.

That the agencies of the Labor Department be instructed to allocate their resources so that priority is given to protecting workers from hazards, discrimination, and joblessness.

That DOL reductions in force and downgradings be stopped.

And that the committee look skeptically at the recommendations made to it by the Department which has shown no sympathy for its basic mission of protecting workers.

That concludes my statement.

Senator INOUYE. I thank you very much, Ms. Taylor. I am certain you will have sympathetic consideration here.

STATEMENT OF MATILDA A. BABBITZ, EXECUTIVE DIRECTOR, AMERICAN ASSOCIATION OF OCCUPATIONAL HEALTH NURSES

PREPARED STATEMENT

Senator INOUYE. Our next witness is Ms. Matilda Babbitz, the director of the American Association of Occupational Health Nurses.

Ms. BABBITZ. Thank you.

Senator INOUYE. What is COHN?

Ms. BABBITZ. Certified occupational health nurse. That's the certification the nurses have now.

Senator INOUYE. It looked like a name.

Ms. BABBITZ. Yes; I know. We have a big problem as to whether to put periods after the initials so people will know it's not a name.

Senator INOUYE. At this time, your complete statement will be made a part of the record.

[The statement follows:]

STATEMENT OF MATILDA A. BABBITZ

On behalf of the thousands of professional occupational health nurses working in American business and industry, I want to express appreciation to the members of this subcommittee for giving me an opportunity to share with you some of the issues that are important to the profession that I represent.

The contributions that occupational health nurses make to the health and safety of America's workers are significant. At the same time, professional nurses are helping employers hold down costs associated with workers' compensation claims resulting from work-related injury and illness, absenteeism and personal health insurance. Other benefits to employers include increases in productivity and employee morale.

Occupational health nurses in 1984 are involved with two major concepts: conserving, promoting and restoring the health of workers and cost containment.

While most of our colleagues in the nursing profession are concerned with the treatment of illness, occupational health nurses are primarily concerned with the prevention of illness and injury. In the workplace, we deal with a well population. It is our role to develop, promote and manage programs that contribute to the ability of America's working men and women to maintain good health.

Most of us would agree that this is a noble pursuit. We would most likely agree further that programs designed to hold down business costs benefit everyone in our society.

What seems less likely to receive universal agreement is the notion that occupational health nurses play an integral part in developing and implementing the overwhelming majority of health programs in business and industry.

During the past year, the American Association of Occupational Health Nurses has, on numerous occasions, expressed grave concern about what we regard as a serious misunderstanding by officials of the Occupational Safety and Health Administration of how occupational health programs in this country are managed.

In OSHA's Hazard Communication Standard, published last November, the section on Trade Secrets excluded nurses from the definition of "health professional" and denied nurses access to specific chemical identities in non-emergency situations.

In the "Summary and Explanation of the Standard," OSHA says it has determined that it is "more appropriate, given the competing interests balanced in this standard, to entrust such information to the physician to whom a nurse would normally report."

The process that produced this language reflects an alarming absence of knowledge about American workplace realities for the following reasons:

- * Most occupational health nurses do not report to physicians.
- * Most occupational health nurses have management responsibilities for occupational health programs.

- Most occupational health nurses function as independent health care providers using off-site medical direction in the form of signed protocols.
- Most occupational health nurses routinely conduct medical surveillance of exposed employees and select personal protective equipment, the very activities that require the disclosure of hazardous chemical identities.

AAOHN believes that the exclusion of nurses from this definition is insulting to the profession of nursing. But, more importantly, this omission works against the best efforts of occupational health nurses to protect the health and safety of workers while attempting to contain costs for employers.

OSHA's definition of "health professional" includes physicians, industrial hygienists, toxicologists and epidemiologists. In most occupational settings, none of these health professionals is present. It is the occupational health nurse who is at the worksite to provide health care. OSHA's standard simultaneously endangers the health of workers and creates an unnecessary economic burden on employers who will be forced to obtain the services of other health professionals to perform functions that occupational health nurses are qualified to do and are currently performing.

In addition to the Hazard Communication Standard, OSHA's recently-published Comprehensive Health Policy reflects the absence of understanding at OSHA of either the qualifications or the role of occupational health nurses.

Occupational health nurses should be involved in consultation and training to assist employers with the management and development of health programs. This provision is absent from OSHA's comprehensive policy.

Occupational health nurses should be involved in developing courses and serving as faculty for OSHA's training institute. This, too, is missing from OSHA's policy.

In addition, occupational health nurses should be involved in the development of standards for the delivery of clinical occupational care. Again, OSHA's policy omits this provision.

AAOHN understands that the members of this subcommittee cannot force OSHA to change either the Hazard Communication Standard or the Comprehensive Health Policy. We are pursuing these matters through proper legal and administrative channels.

The hazard standard and the health policy are simply examples of a very serious problem, a problem that adversely affects the health of our workers and the economy of our nation. And we believe that these are issues that this subcommittee can properly address.

As a professional association, AAOHN is attempting in numerous ways to correct the problems that I have cited.

For example, I met last month in Salt Lake City with members of the National Advisory Committee on Occupational Safety and Health (NACOSH). Following my presentation, NACOSH members unanimously passed a resolution stating that the committee "recognizes the occupational health nurse as one of the health professionals which have a vital role in occupational safety and health."

We appreciate the action taken by members of NACOSH and celebrate a symbolic victory. That victory will remain merely symbolic until OSHA decides to follow the advice of its legally-constituted advisory committee.

In addition to seeking the support of NACOSH, AAOHN is working with representatives of OSHA to set up a series of site visits for members of OSHA's administrative staff for them to witness, first-hand, the activities of occupational health nurses.

We hope OSHA officials will participate in this project. We believe that their cooperation will represent a willingness to correct their shortcomings and to acquaint themselves with the realities of the workplace. However, their expressed interest in involving themselves in this way also represents an acknowledgement that OSHA cannot operate intelligently without the expertise that occupational health nurses possess.

AAOHN is, therefore, respectfully requesting the assistance of the members of this subcommittee in the attainment of one of our most crucial recommendations: that OSHA employ qualified occupational health nurses at administrative staff levels equal to that of physicians in the agency. We are convinced that the absence of occupational health nurses from the decision-making process at OSHA produces a corresponding absence of understanding of the role of the occupational health nurse in providing health care to America's workers.

During our meetings at OSHA, senior officials have indicated a willingness to support the recommendation to bring one or more occupational health nurses onto the agency's administrative staff. The stated problem is budget.

We are, therefore, making an appeal to the distinguished members of this subcommittee to do all that is within your authority to make it possible for the Occupational Safety and Health Administration to employ one or more occupational health nurses on its administrative staff.

We believe that when occupational health nurses are brought into the mainstream of the decision-making process at all levels, the health and safety of America's workers will be protected and the economic interests of the nation's employers will be defended.

Thank you again for allowing me to present the concerns of the nearly 12,000 members of the American Association of Occupational Health Nurses.

Ms. BABBITZ. I would like to thank the committee on behalf of the professional occupational health nurses who provide health care to workers in American business and industry.

The contributions that occupational health nurses make to the health and safety of America's workers are significant. At the same time, professional nurses are helping employers to hold down costs associated with workers' compensation claims resulting from work-related injury and illness, absenteeism, and personal health insurance. Other benefits to employers include increased productivity and employee morale.

Occupational health nurses in 1984 are involved with two major concepts: Conserving, promoting, and restoring the health of workers and cost containment.

While most of our colleagues in the nursing profession are concerned with the treatment of illness, occupational health nurses are primarily concerned with the prevention of illness and injury. In the workplace, we deal with a well population. It is our role to develop, promote, and manage programs that contribute to the ability of America's working men and women to maintain good health.

During the past year, the American Association of Occupational Health Nurses has, on numerous occasions, expressed grave concern about what we regard as a serious misunderstanding by officials of the Occupational Safety and Health Administration of how occupational health programs in this country are managed.

In OSHA's hazard communication standard, published last November, the section on trade secrets excludes nurses from the definition of health professional and denies nurses access to specific chemical identities in nonemergency situations.

In the "Summary and Explanation of the Standard," OSHA says that it has determined that it is "more appropriate, given the competing interests balanced in this standard, to entrust such information to the physician to whom a nurse would normally report."

Senator INOUYE. I can assure you this will change.

Ms. BABBITZ. This has been repeated several times by OSHA's representative that this was intentional and deliberate. That's been published in two magazines and journals.

The process that produced this language reflects an alarming absence of knowledge about American workplace realities for the following reasons:

Most occupational health nurses do not report to physicians.

Most occupational health nurses have management responsibilities for occupational health programs.

Most occupational health nurses function as independent health care providers using off-site medical direction in the form of signed protocols.

Most occupational health nurses routinely conduct medical surveillance of exposed employees and select personal protective equipment, the very activities that require the disclosure of hazardous chemical identities.

AAOHN believes that the exclusion of nurses from this definition is insulting to the profession of nursing. But, more importantly, this omission works against the best efforts of occupational health nurses to protect the health and safety of workers while attempting to contain costs for employers.

In addition to the hazard communication standard, OSHA's recently published comprehensive health policy reflects the absence of understanding at OSHA of either the qualifications or the role of occupational health nurses.

AAOHN understands that members of this subcommittee cannot force OSHA to change either the hazard communication standard or the comprehensive health policy. We are pursuing these matters through proper legal and administrative channels, but we certainly would welcome your support in any way.

The hazard standard and health policy are simply examples of a very serious problem, a problem that adversely affects the health of our workers and the economy of our Nation. And we believe that these are issues that the Subcommittee can properly address.

I assume that the complete statement will be part of the record.

Senator INOUYE. Yes; I have already made that note.

Ms. BABBITZ. I just want to tell you, in my remaining time, that in my discussion with regards to the occupational safety procedure that because of the lack of professional nursing input on their staff, they did not have any knowledge of how occupational health nurses function in the work setting.

And the former Assistant Secretary said that he thought that it would be very nice to have an occupational health nurse on his staff to advise them. I received a telephone call saying that they were proceeding with personnel action to develop a position description, but the positions were frozen and, therefore, although they wanted to, they could not.

And that is really the major purpose of our presenting this purpose to the subcommittee. We are hoping that somewhere in their appropriations they will find a little money to develop a nursing position.

Senator INOUYE. We shall refer, also, to NIH, to medicare/medicaid where nurses are considered professionals.

Ms. BABBITZ. Well, thank you, Senator.

Another area that we had been discussing with them is nursing representation on the National Advisory Committee on Occupational Safety and Health, and we were allowed to make this statement to that committee. And you might be interested to know that the committee passed a resolution, following our presentation, which said that they recognize the occupational health nurses and they have a vital role in occupational safety and health. So that their own advisory committee is advising them to do that. Another activity that has been offered to them is outside visits to occupational settings in industry where members of OSHA's staff can observe occupational health nurses providing health care for workers, since they have the mistaken impression that almost all of this direct care is provided by physicians.

We have not had a response from them on this. They are again attempting to find money. Their travel moneys are restricted. They tell us while they would like to have senior staff members visit occupational health settings, they are looking for funds to do that.

This generally completes the statements that I have to make about our testimony. We are attempting to work with them. They have accused us of being too political, but we feel that we have to behave in that way in order to get them to respond and realize that nurses are indeed health professionals, and we are health professionals who provide most of the direct and primary health care in the work place.

Senator INOUYE. You have many supporters here.

Ms. BABBITZ. Thank you.

PREPARED STATEMENTS

Senator INOUYE. Thank you very much. Your statement will be included in the record at this point, along with other statements submitted for the record on appropriations for the Department of Labor.

[The statements follow:]

STATEMENT OF DAVID M. COONEY, PRESIDENT AND CHIEF EXECUTIVE OFFICER, GOODWILL INDUSTRIES OF AMERICA

Goodwill Industries of America, Inc. (GIA) is a nonprofit organization of 176 rehabilitation facilities in North America with 43 affiliates in 30 countries outside of North America. Our members provide a wide variety of rehabilitation services, including: vocational evaluation, job training, employment, counseling, job seeking skills, and placement services. We welcome this opportunity to submit our recommendations for FY 1985 appropriations for rehabilitation and job training programs.

Before we address our appropriations recommendations, we would like to comment on two areas of interest to the rehabilitation community: the Office of Special Education and Rehabilitative Services (OSERS) transition plan, and the Social Security Administration's vocational rehabilitation program.

We would like to take this opportunity to reiterate our support for OSERS' program to assist disabled youth with the transition from school to work. We applaud both Congress and OSERS for reemphasizing the need for adequate services for youth adults leading to competitive employment. The basic mission of Goodwill Industries is to provide employment opportunities for disabled individuals through our society. Competitive employment for these individuals is an essential element in our programs. Thus, the OSERS transition program is closely linked with our purposed as well as with those of other organizations in the rehabilitation community.

However, we believe the existing service system should be utilized to provide the transition with ongoing services emphasized by OSERS. These transition services should complement successful training and placement programs and should not lead to a replication of existing structures. For instance, time-limited transition services such as Projects With Industry are a good example of successful methods to increase employment opportunities for severely disabled individuals. We agree that time-limited services need to be improved and hope that the linkages between vocational rehabilitation, special education, and vocational education will continue to be strengthened. At the same time, innovative employment and training programs should be integrated with new transition programs designed to emphasize work opportunities and ongoing support services.

Our second concern is with the Social Security beneficiary rehabilitation program authorized by sections 222(d) and 1615(d) of the Social Security Act. As you know, this program was drastically curtailed after enactment of sections 2209 and 2344 of Public Law 97-35, the Omnibus Budget Reconciliation Act of 1981. Prior to enactment of P.L.97-35, the beneficiary rehabilitation program was funded at $124 million, but now is funded at approximately $6 million. The 1981 amendment provided that rehabilitation providers may be paid for services provided to eligible SSDI or SSI beneficiaries only where the beneficiary works for nine continuous months after the provision of services.

The effect of this provision has been to reduce services to beneficiaries especially to those disabled individuals with severe impairments to work. With payment made only for successful rehabilitations, service providers have little incentive to risk rehabilitating severely disabled individuals. However, the need for vocational services for SSI and SSDI beneficiaries still exists and is not readily met through the federal-state rehabilitation system, which is mandated to serve a different segment of the disabled population.

We urge the members of the Committee concerned about the beneficiary rehabilitation programs to work with members of the Finance Committee on this problem. Although minor improvements to the program are contained in pending disability reform legislation (H.R.3755, S.476), we would hope that a comprehensive solution to the current problem could be reached during the 98th Congress.

The following appropriation recommendations parallel those made by the Consortium for Citizens with Developmental Disabilities, a coalition of national disability and rehabilitation organizations in which we actively participate. Our recommendations generally reflect the needs of the programs and current authorization levels.

Although we strongly support the full range of government programs for disabled individuals, we wish to highlight a few of our recommendations in this statement.

Rehabilitation Act Programs

The Basic State Grant program authorized by the Rehabilitation Act, as amended, provides formula grants to State vocational rehabilitation agencies to help disabled individuals become employed and self-sufficient. The Rehabilitation Act emphasized that severely disabled individuals are to be given priority in the provision of these services.

Since fiscal year 1970, there has been a steady decrease in the number and types of disabled individuals receiving rehabilitation services, due in large part to inflationary erosion and the greater costs associated with serving severely disabled individuals. Yet the Administration has proposed to freeze Basic State Grant funding in FY 1985 at the FY 1984 level of $1,003.9 million. We urge the Committee to reverse the decline in rehabilitation services by increasing funding for Basic State Grants in FY 1985 to $1,117.5 million.

Projects With Industry (PWI) is a cooperative program between businesses and the rehabilitation community to train and place disabled individuals in competitive employment. In FY 1983, 72 RSA-PWI projects placed over 10,000 disabled individuals in competitive employment, with a retention rate of over 75 percent. GIA has successfully operated PWI programs in cooperation with RSA and the Department of Labor for several years. During our last grant year, GIA's seven RSA-PWI funded sites around the nation placed 187 disabled persons into jobs, using only $155,000 and exceeding our placement goals. The retention rate for individuals placed by our programs ranges between 78 to 82 percent.

We believe that the Administration's FY 1985 request of $11.2 million for the PWI program should be increased and that PWI be funded in FY 1985 at the authorized level of $14.4 million. With the increased emphasis on employing developmentally disabled individuals and expansion of the PWI program to include State agencies, an increase in the program is needed. The program's success and positive beneift in economic and human terms justify the increase.

Job Training Partnership Act

The Job Training Partnership Act (JTPA) has been in effect since October 1, 1983. The JTPA includes provisions for training and placement programs for disabled people as part of the overall training program for economically disadvantaged and dislocated workers (Title IIA). National programs designed to serve the training needs of disabled individuals have been continued under Title IVD of the JTPA from the CETA program. We urge the Committee, during its ongoing oversight of JTPA implementation, to monitor the extent to which disabled individuals and rehabilitation facilities participate in local JTPA programs.

The President's proposed budget for FY 1984 would freeze the JTPA Title IIA grants at the FY 1984 level of $1,886.2 million and would cut the funding for National Activities (Title IVD) from $64.5 million in FY 1984 to $48.9 million in FY 1985.

The proposed reduction in national activities funds threatens the successful programs currently funded and targeted to serve disabled people. In FY 1983, 7 national organizations received $3.5 million from the Department of Labor (DOL) to provide training and placement services to disabled persons nationwide. During FY 1983, GIA placed 942 disabled individuals under our DOL contract. These programs should continue to be funded in order to serve a population often overlooked in a large, decentralized block grant program.

GIA recommends that the proposed FY 1985 spending freeze for JTPA be applied equally so that $1,886.2 million be appropriated for JTPA block grants and $64.5 million be appropriated for national activities in FY 1985.

Attached to our statement is a chart summarizing our recommendations for FY 1985 appropriations for rehabilitation and job training programs. We appreciate the opportunity to submit our statement and thank you for your continuing committment to strengthening programs of vital importance to disabled Americans.

Summary of GIA's Recommendations

(in millions)

Program	FY 1984 Appropriation	FY 1985 Authorization	President's FY 1985 Request	GIA Recommendation
Rehabilitation Services				
Basic State Grants	$1,003.9	$1,117.5	$1,003.9	$1,117.5
Rehabilitation Training	22.0	27.0	5.0	27.0
Independent Living (Parts A, B, C)	19.4	22.0 +such sums	21.0	49.0
Special Projects	12.9	13.6	14.6	13.6
Projects With Industry	13.0	14.4	11.2	14.4
Special Recreation Programs	2.0	2.1	0	2.1
Client Assistance Projects	6.0	6.3	0	6.3
Evaluation	2.0	such sums	0.5	2.5
National Institute of Handicapped Research	36.0	40.0	30.06	40.0
Job Training Partnership Act				
Block Grants	1,886.2	such sums	1,886.2	1,886.2
National Activities	64.5	such sums	48.9	64.5

STATEMENT OF BARBARA H. KURTZ, ORDAINED MINISTER AND STUDENT, UNIVERSITY GERONTOLOGY CENTER, WICHITA STATE UNIVERSITY

Distinguished Chairman and members of the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee:

I am Barbara Kurtz, an ordained minister and presently enrolled in the graduate program of the University Gerontology Center of Wichita State University.

I would like to thank you for the opportunity to express my views regarding the funding of Title IV of the Older Americans Act (Public Law 89-73).

Based on my experience with older Americans, I wholeheartedly support your retention of Title IV of the Older Americans Act (Public Law 89-73) as revised and extended in Public Law 97-115, and to the funding of Title IV for research and training in the field of aging for the next three years.

I concur with the recommendation of the Gerontological Society of America and the Association for Gerontology in Higher Education that the minimum levels of funding for the next three years be: $40 million for FY 1985, $45 million for FY 1986, and $50 million for FY 1987. This level of funding is needed in order for Title IV to accomplish its stated purposes.

The present funding of Title IV in the amount of $22.2 million for FY 1984 is a reduction of 59% from FY 1980. The present Administration's proposal of $5 million for FY 1985, representing a 92% decrease from FY 1980, is entirely inadequate to carry on the functions of Title IV. There are several reasons for its being adequately funded.

1. The departments or centers of gerontology in the universities are relatively new (less than ten years old); they need this support in order to "get their feet off the ground." Universities are still working for the recognition of gerontology as an academic discipline. Departments of gerontology need to

be established in more universities in order to train the personnel which will be needed in the field of aging in the immediate future. Assistance is needed for training programs in a field that has not had a long academic history.

2. In this new field, trained personnel are needed to provide more services for the elderly so that service programs will be well managed or be developed in the first place. If we are to have trained leaders in the field of gerontology and have the personnel needed in service organizations, on university campuses and on the national level in the years to come, we must use our resources now for the education of potential and present leaders in the field. Having worked almost twenty years in leadership development in a developing nation overseas, now independent, I know the value of expending funds for training personnel.

Without trained leadership, we cannot be assured of the quality of programs for the elderly. A "band-aid" approach is taken when stopgap measures take the place of the careful planning and research which require trained leadership. More than ten years ago, Senator Harrison A. Williams, Jr. of New Jersey in a hearing in the Special Committee on Aging of the U.S. Senate (6/19/73), said: "Programs for older Americans cannot function well unless they are directed by trained personnel with some understanding of the needs of older Americans."

3. Another reason for the need for adequate funding of Title IV research and training programs is that of the sheer numbers of older persons in our society. It is well known that there will continue to be a great increase in the numbers of older persons in our population in the years to come, especially of the group called the "old-old," 80 years of age or older. This calls for a continued increase in the number of trained service providers in the field of aging. It also calls for more research into the process of aging, which we are only beginning to understand at the present time.

CASE NARRATIVES

1. The University Gerontology Center of Wichita State University where I am presently enrolled, now has state-line funding for its staff. However, other univerisities need major grants to help establish centers or departments of gerontology. The program at Wichita State is an example of the kinds of programs which should be funded and developed in a number of universities across the nation.

a. Projects of limited duration: These include research projects, such as an assessment of the needs of older area residents currently being conducted in cooperation with the Sedgwick County Department on Aging; continuing education, often conducted in cooperation with and/or at the request of agencies and organizations working with elderly people; and The Governor's Conference on Aging, in which the University Gerontogy Center worked closely with the Kansas Department on Aging in the planning, and which Wichita State University hosted in 1982 and 1983.

b. Development of permanent activities related to aging: one is the gerontology academic program itself. Another example is the University Gerontology Center's Mullikin Resource Center, which houses a collection of more than 5,750 documents in more than 70 subjects related to aging and provides instructional support for WSU courses in gerontology and for continuing and inservice education activity in the area of aging. The Center is used not only by WSU students and faculty, but also by planners and providers of services for the aging, private individuals, and students from other institutions of higher education in Wichita and across the state. Another project which received initial funding for its development is the 20-page tabloid newspaper "Active Aging," which is distributed monthly at no charge to most persons aged 60 and older in the tri-county area which comprises the Central Plains Area Agency on aging, and to planners and providers of services to the aging. Presently the newspaper is funded by the Central Plains Area Agency on Aging and by revenues from advertising.

c. The University Gerontology Center also serves as a resource for community agencies in the field of aging. It has formalized working relationships between the Center and 37 agencies and organizations in the city and across the state. The Center, through these agreements, assists the agencies and organizations in conducting research, cooperates in providing continuing education and inservice training, assists in proposal preparation and serves as an information source. These same agencies also receive gerontology majors into their staff as interns, the students to gain practical experience and the agencies receiving temporary additional staffing.

2. Although the University Gerontology Center of Wichita State University now has state-line funding for its staff, it must continue to have external funding in order to develop and coordinate aging-related academic, research, and service activities and programming at the university, and to assist other academic units in developing gerontological subjects. The Center also needs external funding for the future development of permanent activities related to aging. If adequate funding is not continued, the capacity to provide technical assistance to developing community programs will be seriously curtailed.

Senator Williams, in the hearing previously cited, testified, ". . . it is readily apparent that our universities should also produce fresh concepts that will help our society's adjustment to the sweeping changes that are occurring as the percentage of our 65+ population continues to increase with each passing year." His statement is as true today as it was ten years ago. Funding levels affect not only the university but the community and our society as a whole.

3. I would like to close with a more personal testimony. Several years ago I was assigned to pastor churches in two

small communities in a county in northern Kansas. According to the 1980 census, over 20% of the population in that and surrounding counties is 65 years of age or older. Through the cooperation and assistance of the Northeast Kansas Area Agency on Aging, I was able to help in getting some programs for the aging started in these communities. It was in this context that I realized the need for further training in order to better understand the needs of the aging population and to more effectively assist and counsel the elderly. Through these experiences I sought out further training in the field of aging, and enrolled in the program offered by the University Gerontology Center of Wichita State University. Other pastors have also told me that they feel the need for more training in the field of gerontology in order to more effectively serve the people in their congregations.

Training in gerontology, therefore, means not only training persons who work in agencies and organizations directly concerned with assisting the elderly in some way. It also means training professionals in other fields as well: doctors, lawyers, ministers, librarians, to name only a few. Whatever the profession, all those who come in contact with the public will increasingly be working with the aging population, and will need to know what their needs, interests, and desires are if they are to serve effectively. Continued funding of Title IV will ultimately provide training for these people at the grass-roots level.

SUMMARY

There is a story to the effect that if you give a man a fish, you provide him with one meal; if you give him a fishing pole and teach him to fish, you are providing for unlimited future meals for himself and his family. We need adequate funding for Title IV not just to train one or a few groups of gerontology students or to fund one research project or another. The proposed funding of Title IV for FY 1985 at $5 million is entirely inadequate to fulfill the mandate of training and recruiting personnel, establishing and supporting multidisciplinary centers and to support research and development projects in the field of gerontology except on a very limited basis. We need the funding proposed in this testimony to implement the provisions of Title IV at adequate levels.

In conclusion, I would like to thank the committee for this opportunity to testify on the need for funding Title IV of the Older Americans Act at adequate levels for the next three years.

LETTER FROM PHILIP POLIVCHAK, PRESIDENT, HOME BUILDERS INSTITUTE

February 29, 1984

The Honorable Lowell Weicker, Chairman
Senate Subcommittee on Labor, Health
and Human Services and Education Appropriations
131 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Weicker:

On behalf of the Job Corps operating and vocational contractors, we respectfully request that this letter and the enclosed testimony be entered into the Fiscal Year 1985 budget hearing record of the Senate Subcommittee on Labor, Health and Human Services and Education Appropriations.

The current Job Corps 1984 Program Year appropriation of $577.5 million is inadequate. We are able to keep centers operating at full capacity only with the use of carry in funds which will be fully expended by the end of the 1984 Program Year. There are no funds to support desperately needed repairs on deteriorated facilities at many centers. Compounding the ever worsening situation is the great backlog of unemployed youth seeking entrance into Job Corps.

As you are aware, the President's 1985 budget submission recommends an increase in Job Corps budget authority for Fiscal Year 1985. It states that $600 million will maintain the current slot level only if stringent cost-cutting measures are instituted. The budget documents are firm in their conclusion that "Should circumstances prevent these savings from being fully realized, the size of the Job Corps program and the planned number of training service years will of necessity be reduced accordingly."

Congressional budget committee personnel have advised us that a minimum of $634 million is needed in Fiscal Year 1985 to continue the program at its current operational level. At this minimum funding level of $634 million we can support an enrollee level of 40,544 service years, but there will be no funds to repair unacceptable facilities. Only the highest priority health and safety accomodations will be made.

Chairman Weiker, we urge your immediate attention to this assessment of the deteriorating state of Job Corps. We ask for your leadership in bringing Job Corps to a respectable and equitable Fiscal Year 1985 funding level.

Sincerely,

Philip Polivchak
President

STATEMENT OF JOHN W. GAINES, PRESIDENT, TELEDYNE ECONOMIC DEVELOPMENT CO.

Introduction

Teledyne has been operating Job Corps Centers for the past eighteen (18) years. We currently operate Centers in Phoenix, Arizona; Tucson, Arizona; Albuquerque, New Mexico; Roswell, New Mexico; Guthrie, Oklahoma, Pittsburgh, Pennsylvania; Grafton, Massachusetts; Gainesville, Florida and Jacksonville, Florida. The following statement covers:

Job Corps Budget and Personnel
Basic Job Corps Programs
Job Corps Center Facilities
Additional Job Corps Programs

All of the following comments concern TRAINING. Training is what this program is all about. The Job Corps enrolls disadvantaged young people (ages 16-21) who are usually high school dropouts -- with no place to go but down -- and trains them. Trains them to be PRODUCTIVE - EMPLOYABLE CITIZENS. It is not an easy task. It is a task this country cannot afford to ignore. It is a task that is now being done by JOB CORPS. The direct and indirect dollar return to the United States Taxpayer far exceeds the cost of this program.

Job Corps Budget and Personnel

Job Corps is the most successful social laboratory in the country to research and implement methods of breaking the poverty cycle. The great strides made by the program over the past eighteen (18) years have proven this repeatedly. If a corpsmember is to succeed in a job, he or she, must possess skills in five interrelated areas: Vocational, educational, physical, living and social. This is what Job Corps provides. As Mathematica Policy Research of

Princeton, New Jersey has found, "the average investment per corpsmember is paid back in approximately three years". With the proven success rate of the more than 1,000,000 youngsters who have profited by Job Corps, it can be truly said that congressional appropriations have been and continue to be well spent. In terms of real dollars, the budget for Job Corps has decreased over the years but Job Corps has steadily improved its program. I hardly need say that the employment situation for the youth of this country needs special attention. Basic skills and attitudes necessary for employment are of utmost importance. Job Corps is a successful vehicle for providing disadvantaged youth with these skills. It is an outstanding demonstration of the joining of industry, labor, government and youth into a successful program. Budget considerations continues to plague us all. I am sure that when your committee reviews the Job Corps budget for FY'84 and future years, this worthwhile program will receive the consideration it deserves.

A matter of concern in the personnel area, is the current DOL "RIF" policies. The loss and replacement of DOL personnel possessing many years of experience in Job Corps is creating a "knowledge gap" which is hurting this program. We all recognize the tremendous pressure government is under regarding budgets. However, there is a great need for stable and experienced government personnel for this program and I hope all due consideration can be given to maintaining qualified DOL staff.

Vocational and Skills Training

The vocational learning environment at Job Corps Centers manifests the philosophy of individualized training, complimented by the development of skills and confidence in each corpsmember. The Center's vocational training is designed with a focus on each individual's current position in the working world, his/her employment expectations, and the establishment of realistic goals and development of skills to attain them.

Curriculum insures that individual abilities are exercised in the acquisition of specific skills required for employment. Opportunity is continually available to practice these skills in order to stimulate motivation. Motivation is further increased through progressive accomplishment of tasks. All training experiences are directly supported by vocationally related reading and math.

Job Corps is well aware that conventional methods of training have not worked in the Job Corps target population. Therefore, instructional techniques and methods are designed to cope with corpsmembers who have a history of difficulty in training or negative attitudes toward it.

The Job Corps Program teaches young people how to work. Job Corps has been a national leader in developing competency based vocational programs within the system. This vocational improvement effort with all its thrust must be maintained. I urge the Senate to take special care to see that these efforts of the Department of Labor continue to receive the necessary attention for success.

Basic Education

The Job Corps education program emphasizes basics. Reading and math skills are stressed. The acquisition of a GED, for those without a high school diploma, is paramount for job placement in many occupations. Training in other social and living skills takes place to address behaviors which have caused the youth problems at home and at work.

We have developed within Job Corps a very strong and successful basic education program geared towards individuals moving at their own pace to reach common goals. The GED program developed for Job Corps is utilized by many non-Job Corps organizations. Teledyne is particularly proud of a Learning Disabilities program developed by the Gainesville Center in conjunction with the University of Florida. This program is the most extensive one of its kind dealing with adolescent learning problems. It will soon be utilized nationally. These programs illustrate the Basic Education areas strengths.

Job Corps has designed a program that blends superior instruction with sensitivity to the needs of the disadvantaged young person. Learning is made interesting, individualized to the corpsmember's abilities and interests, and geared to the demands of the job market.

Job Corps defines learning as an interaction with one's environment that prompts a change in behavior. The challenge for the Job Corps staff is to direct corpsmember's interactions with their environment so as to help them deal more successfully with the working world.

Job Corps taps corpsmember's innate capacity to master tasks they have not attempted. First, it stimulates their desire to learn and persevere in the task; and, second, it allows them the time their abilities require to master it.

Accordingly, Job Corps is guided by the following precepts in designing the Job Corps Center's educational training program to be of greatest benefit to the corpsmembers:

- Individualized instruction promotes effective learning.
- Most corpsmembers can master the learning task if it is presented effectively and if they are allowed as much time to practice and absorb it as their individual ability requires.
- In order to be mastered, a learning experience must be meaningful to the learner. Instructors should continually demonstrate how the subject matter will be useful to corpsmembers.
- Learning is measurable and should be measured.
- Effective learning requires the learner's active participation.
- The goal of learning is to enable the learner to apply knowledge, skills, or attitudes to his/her own life.

The education staff of the Job Corps gives all corpsmembers individual attention to insure that they have the opportunity to leave the program with a GED, to master the skills needed to locate and progress in a job that offers upward mobility, and to attain the self-confidence and knowledge necessary to live independently while working with others in our society.

To meet corpsmember's needs, the education staff works closely with individual corpsmembers in three main areas:

> Academic education (math, reading, and GED)--to help corpsmembers acquire all the knowledge and skills they are capable of attaining.
>
> Vocational support to prepare corpsmembers with the skills necessary to find and keep the job that offers upward mobility. The academic education staff works with the vocational staff in developing vocational vocabulary sheets and writing corpsmember activity guides to enable corpsmembers to understand the vocational materials used in the various shops.
>
> Social development to encourage personal growth, social skills, and independence.

These three areas work in conjunction with all components of the Center to assure that corpsmembers receive a well developed and thorough training experience.

Residential Living

The aspect of Job Corps which truly distinguishes it from the majority of other training programs is its residential element. Center Life includes many components -- counseling, orientation, recreation, health services, enrollee support, and, of course, residential living. All of these areas assist the youth to live independently after leaving the program.

During the past three (3) years, Job Corps has made a concerted effort to improve this area. A Training Academy for Residential Advisors has been established at the Clearfield, Utah Center. Emphasis has been placed on group dynamics and intergroup relations. The residential living program is designed to provide corpsmembers with the maximum opportunity to develop patterns of living that help them succeed in their educational and vocational training and build a rewarding personal life. Positive behavioral change can be produced only in an environment of trust, confidence, and successful experiences. The residential program provides a base of stability, must motivate the corpsmember to change unacceptable behavior, and continues long enough for the corpsmember to feel comfortable and secure in new patterns of living and behavior.

To create such an environment, Job Corps has designed the residential living program to meet the following objectives:

> Provide each corpsmember with safe, secure, and healthful physical surroundings.
>
> Enable each corpsmember to better cope with the demands of living as a responsible member of society and to relate to peers and authorities.
>
> Provide professional counseling to meet individual needs.
>
> Promote interest in productive leisure experiences.

> Reinforce positive behavioral change by giving praise, privileges, and greater responsibility.

Desired corpsmember behavior is maintained by specifying a minimal number of rules consistent with Job Corps requirements, acquainting staff and corpsmembers with the need for them, and training the staff in enforcing them appropriately.

Physical Plants

The physical plants of Job Corps are as diverse as there are Job Corps Centers. Continuous work needs to be done on these sites to keep them at proper health and safety levels for corpsmembers in their training. I urge continued attention to the Job Corps facilities which now exist.

Equipment Needs

As well as Job Corps does in its vocational training efforts, it has been hampered by the lack of funds to utilize current training equipment. Corpsmembers, when placed on Work Experience, are often confronted with machinery they have never seen. We view the ability of Job Corps to keep current with the needs of the vocational trades now being offered at Center's as one of the most important requirements of the future Job Corps vocational program.

Pre-Military

Teledyne supports the proposed relationship between Job Corps and the various branches of the Armed Services. Our understanding of the program, is that youth which attempt to enlist but fail the Armed Services Vocational Appitude Battery are referred by the military recruiter to the Job Corps program. These youth will be sent to selected centers to receive up to a year of academic and pre-military training (no weapons). After such training and assuming the individual can now pass the ASVAB, he/she will be inducted into his/her selected military branch.

Pre-military enrollment in Job Corps by youth interested in joining the armed forces should be encouraged. The system will provide these pre-military youth training with their peers. Job Corps can contribute significantly to the military readiness of the country by the use of its basic skills program. The adjustment that youth can make during their group life experiences will profit the military in many different ways. I urge the support of this program as it enters its first phase of experimentation.

National Training Academies

During the past two years, the Residential Training Academy located at the Clearfield Job Corps Center has trained residential staff from across the country in successful techniques to manage Center Life programs. All staff from Teledyne Centers who have attended have greatly complimented their training experience. We support this program and urge its continuance.

Advance Career Training

The ACT Program, while in existence from 1978 through 1981, gave those qualified corpsmembers an opportunity to enroll in college and fully realize their potential. Teledyne believes that the Advanced Career Training Program (ACT) is a very worthwhile adjutant to basic Job Corps. We strongly recommend that this program be continued within budgetary considerations.

In closing, I would like to comment to this Committee, that Job Corps may be compared to another program supported by Congress. I compare the Job Corps program with the GI Bill which was passed shortly after World War II. The GI Bill legislation has proven to be one of the wisest legislative bills passed and supported by Congress in this century. I believe Job Corps, although on a smaller scale, can be included in this category.

Thank you for this opportunity to share with you, my insights concerning Job Corps.

STATEMENT OF H.W. WATKINS, PRESIDENT AND GENERAL MANAGER, THE SINGER CO.

I am Herbert W. Watkins, Vice President and General Manager of the Career Systems operation of The Singer Company. Singer currently manages 12 Job Corps centers under contract to the U.S. Department of Labor, through its Employment and Training Administration. Two years ago, we operated an equal number of vocational assessment and training programs funded through various titles of the CETA legislation. We are marketing similar programs and related products to the newly formed JTPA service delivery areas, as well as to other government agencies, to the military and to industry, principally in the United States. We have also operated programs in the public schools, in vocational rehabilitation facilities and in correctional institutions.

The Job Corps program remains our base of greatest experience, as well as the largest percentage of our annual sales. I personally became involved with Job Corps when it was still under the auspices of the Office of Economic Opportunity. In its almost 20-year history, the program has come under attack several times, from different Administrations. It has survived largely because of widespread and bipartisan Congressional support engendered by the program's effectiveness with the disadvantaged young men and women who have enrolled in Job Corps.

I am not concerned now as to the program's continuation as much as I am about its possible erosion from the desire for cost savings regardless of the ultimate expense to this program.

The Job Corps budget in the Fiscal Year 1984 appropriations bill, the lowest in recent years, results in a 10 percent cut from the 1983 operating budget. The reduction is even greater for program year 1985, because there will be no carry-in monies nor is there any provision, in either year, for an inflationary factor.

Job Corps has also suffered serious personnel reductions, particularly at the Regional Office levels. In the five years between 1978 and 1983, the number of enrollees increased 82.8 percent and the number of centers expanded by 77.9 percent. Authorized positions in Job Corps Regional Offices, however, decreased by 42.8 percent. Experienced Job Corps staff have been "bumped out" by senior transfers from other ETA functions--generally CETA and Employment Service. The majority of these individuals do not appear to have the same interest or competency, based upon experience, of those they replaced. The contractors' job has been made more difficult in light of this lack of knowledge and continuity for evaluating bid proposals, selecting contractors, conducting center reviews and acting on requests for approval. There are increasing requirements for the contractors, with less capability for corresponding responsiveness by the government.

I believe that the contractors are operating centers under the maximum degree of accountability possible. Extensive audits have been conducted during the past year. Despite some preconceived notions to the contrary, the audits simply did not uncover any significant mismanagement of government funds, nor did they indicate fraud or abuse on the part of Job Corps operators. At Singer's largest center, the auditing of over $121,693,780 expenditures, covering eight contract years, found absolutely no disallowed costs and, more surprising perhaps, zero dollars of questioned costs.

Another area of concern to the Congressional districts where centers are located is the occurrence of significant incidents, ranging from assaults and other serious criminal actions to those which may simply lead to negative and often uninformed media or citizen attention. I submit that the number of serious incidents committed by the young people in Job Corps is far less than the rate of occurrence among similar populations in the public schools. I believe that it is time that this matter be put in proper perspective in regard to its not becoming a "witch hunt" issue diminishing the much more significant and positive actions of these young people during their Job Corps enrollment. I would urge also that operators of Job Corps centers should be provided a degree of protection from third-party law suits, as is the government under the Federal Tort Claims Act. Our corporate attorneys have drafted such a possible amendment to the Job Training Partnership Act.

Another area that private business contractors, particularly those representing large industrial corporations, should be concerned about is the quality of the vocational training. I personally believe that the true mission of Job Corps remains the same as that of the Job Training Partnership Act, which is, training leading to gainful employment. We must upgrade the centers' training facilities, equipment and teaching methods and make certain that we are training in the correct skills needed by employers today and in the near future. The Ford Foundation has been warning us for some time that technical skill requirements for entry-level jobs are rising. Singer's recent work with two JTPA Dislocated Worker programs confirmed that companies are using technology and their work forces to improve their productivity and quality control. Less skilled workers are simply in less demand. Job Corps and JTPA must acknowledge this reality.

Clearly, the residential nature of Job Corps adds to its cost, through related support staff, facilities and functions. Just as clearly, residential living at Job Corps provides an opportunity for the individual youth to mature, much as for the college student away from home for the first time. It is especially necessary for young people in this population--many of whom have home environments and peer group influences that have produced negative attitudes toward learning, work and society's objectives of responsible citizenship. By contrast, Job Corps dormitory life fosters cooperation, racial/ethnic understanding, and a pride and respect for one's living conditions.

Many of these Job Corps facilities need improvement. Health and safety codes must be met, certainly, but more attention should be paid, as well, to classroom and other space inadequacies. Corpsmembers in the building trade skills, whether taught by unions, the National Association of Home Builders, or the contractors, are capable of tremendous construction work. If the funding is made sufficient for these projects, existing centers, particularly the older, larger sites, can be improved and even expanded to serve more youths while offering practical training experience.

In closing, this program is proven effective and it deserves protection against inadequate funding or other harmful actions.

STATEMENT OF ROBERT L. MARQUARDT, PH.D., CHAIRMAN AND PRESIDENT, MANAGEMENT AND TRAINING CORP.

It is indeed an honor for me to return to Congress to again testify in behalf of the status of your National Job Corps program. Your program is still the very best alternative offered to unemployed, unskilled youth. It is the most successful and comprehensive accountable training system available in the free world, with a very respectable job placement rate. Reportedly, in FY '83, 50 percent of all enrollees obtained jobs or joined our U. S. military services. In addition, 25 percent pursued further educational or vocational training.

From all over the world, many educational dignitaries visit your Job Corps centers so they can duplicate all or parts of the Job Corps miracle. Your centers provide a needed change of environment for youth who have dropped out of school and have less than average 6th grade reading and math skills. In addition to basic educational advancement, these students learn career skills and develop interpersonal techniques which allow them to succeed in the working world.

What is my reference point to make such a positive claim? As Chairman and President of the Management and Training Corporation (the Education and Training Division of Thiokol until December 1980), I am aware of our staff's contribution to the Job Corps story from its beginning in 1965. We presently operate six model Job Corps centers for the Department of Labor in Atlanta, Georgia; Albany, Georgia; Charleston, West Virginia; Shreveport, Louisiana; Reno, Nevada; and Clearfield, Utah. We have trained over 126,000 corpsmembers and it is conservatively estimated 80 percent of our corpsmembers have been placed on jobs, or into advanced education. Many have entered college or universities and received degrees. Some of our graduates are now operating their own businesses successfully.

Job Corps serves youth from every state, from rural and urban lifestyles, and from all different racial and ethnic backgrounds. Job Corps also serves hundreds of youth from Indochina and, from its beginning, has been international in scope. Of the 4,565 corpsmembers presently enrolled in the six MTC managed centers, 300 are Indochinese. Many corpsmembers, upon arrival, are illiterate or nonfunctional readers and need to acquire the social skills (communication, job responsibilities, work ethic, working with fellow employees, code of conduct) as well as vocational training and upgraded basic education levels.

Job Corps has always been operated on very detailed specifications. That specificity, coupled with ongoing DOL program management and yearly DOL program audits, has assured quality programs. Recently, DOL and Congress also initiated long overdue financial audits. If the results of all centers are like ours, the degree of questioned costs are less than one-half of one percent of contract value and final settlement will be substantially less.

The Job Corps program management by DOL is experiencing continuous erosion of the experienced DOL Regional and Washington staff. Over recent years, many experienced and highly technical program managers of Job Corps have been lost through bumping, riffing, and cuts. Job Corps is a most comprehensive program to operate and manage, and DOL management cannot afford the yearly losses of its trained staff. Every time you lose experienced Job Corps program management in wholesale lots you lose program audit capability, you open the door to unqualified bidders, and you most definitely lower the quality of the program.

Many domestic programs have been terminated or reduced because of shifting priorities at the National level. Many in Congress and in the Department of Labor have said that the Job Corps program has survived because of its high success rate and detailed accountability to prove its high return on taxpayers' investments. "This investment returns approximately 45 percent more than the cost to the taxpayers," as reported in the Evaluation of the Economic Impact, an extensive study conducted by Mathematica Policy Research. This being the case, the program actually makes money for the Government rather than costing. Summary highlights of this report are attached for your review.

Have Job Corps budgets remained adequate? No, they have not! Job Corps contract budgets have been constantly eroded or held at approximately the same level. Yet, medical costs, food, utilities, etc. have increased yearly. Every year contractors are asked to hold the line, give few merit raises, cut the materials, reduce costs, etc. This is proper up to a point, but that approach, year after year, is not economically feasible or sensible. Where can we as managers logically find ways to hold the quality of the program, yet take care of inflation without contract cost increases or minimal ones at best?

Job Corps vitally needs a long-range plan for upgrading facilities and equipment or Job Corps will no longer be as successful nor continue to be a national model for the world to duplicate. Despite the concentrated efforts of contractors to maintain your facilities, some Job Corps center facilities are alarmingly in need of repair and urgently need your attention to obtain an adequate budget level to operate efficiently. Poor facilities and equipment have a direct impact on negative incidents and adversely affect program results.

We have been advised by Department of Labor officials that Job Corps cost per slot for 12 months in FY '83 was $13,262. The current average length of stay is 7.8 months. Thus, the current average cost per each participating enrollee is $8,620. Is that a high cost? It is, in comparison to public school vocational education budgets per student. Ninety percent of the Job Corps enrollees are dropouts from public schools. They are economically disadvantaged and have failed to acquire minimal reading and math skills through the public school system. They certainly are not employable in the employment market of today for other than part-time or temporary work.

I believe that $8,620 is a realistic average cost for each participating student in Job Corps in FY '83. However, I believe it is an unrealistic cost for FY '84 or FY '85. For Job Corps students, there is no other alternative that provides all the necessary components they need to be able to enter the work force. The average cost target to train an adult under JTPA for this FY is $5,900. This training does not provide food, lodging, medical, dental, counseling, clothing, major educational rehab, etc., and for the most part provides only quick entry-level career training. The typical JTPA bid we have examined is for three to four months of preliminary skill training only. I believe that the JTPA cost targets are reasonable for adults with high school diplomas and previous work experience, but that the training time is not. An average training time of six months for JTPA enrollees is more realistic. Job Corps enrollees, 90 percent of which are high school dropouts and needing a change in living environments, certainly do not fit into most state JTPA programs and, thus, have limited rehabilitation alternatives.

For welfare recipients enrolled in Title II-A programs, the Labor Department proposed a job placement rate of 39 percent (Manpower Vocational Educational Weekly dated 5 January 1984); yet, Job Corps places 50 percent of all enrollees on a job or in the military, and 25 percent additional enrollees into further training or colleges.

Job Corps works because of all the various integrated components it offers, plus the necessary change of environment into a highly counseled residential setting. Typical youth training programs without the residential component find absenteeism of disastrous proportions. Deleterious community, home, or gang environments take their toll on skills achievement and attendance of typical dropout youth enrolled in non-residential training programs.

The California Youth Authority data (see attachment) clearly shows the need for change in environment for young adults coming from areas of delinquency, broken homes, etc. Of those youth incarcerated in California in 1982:

- Seventy-two percent came from neighborhoods with high or moderate delinquency,
- Fifty percent had one parent, brother, or sister who had a delinquent or criminal record,
- Forty-eight percent had undesirable peer influences.

Those statistics vividly show why high school dropouts from high delinquency areas and with undesirable peer influences should go to a residential Job Corps center which provides a change to a positive environment for learning.

Much emphasis has been given in recent months to reducing negative incidents. This is good. We should always, as operators of centers, make this a high priority. We have excellent student accountability systems, student incentive systems, and do abide by center and state laws. Students must learn to live and work in a framework of law and order before they can hold jobs and become responsible citizens. However, while we as a contractor do the best job possible to provide a safe environment conducive to learning, negative situations will occur. Every city, town, and school, including the Job Corps center, will always have a small percentage of the population which departs from what is right. Some students will not conform to rules no matter how excellent the motivational factors, the positive school environment, or how qualified or ample the staff.

Mr. Gordon Berlin, program officer of the Ford Foundation, recently stated at the National Governors' Association Conference on employment training policy that, "Forty percent of all unemployed are 16 to 24 years old. Youth unemployment is expected to rise, because the percentage of disadvantaged and minority youth is rising as a percent of the total population."

With our present millions of youth unemployed and "on the street," dare we fail to adequately fund the finest youth skills training and placement program in the United States? Dare we fail to retain our remaining DOL Job Corps experienced staff? And dare we fail to truly examine the quality and cost of the alternatives which include lifetime unemployment benefits and/or the tremendously high cost of incarceration? Incarceration costs for youth in California, for example, cost $21,000 to $24,000 per year.

In conclusion, thank you for this opportunity to address your Committee on Job Corps. Job Corps budgets and training slots should be expanded this year, not cut as they have been in recent years. Its success stories are real, are commonplace, and its failures are few. The Job Corps Charter is for skills training, job placement, and human development ...our unemployed youths' hope... and your investment in America's future.

Senator Hatch, you have repeatedly visited the Clearfield Job Corps Center and are aware of our success with your program. I welcome your Committee to visit any of the centers operated by MTC.

Thank you.

Statement of O.H. Simmons, Corporate Secretary, MINACT, Inc.

My name is O. H. Simmons. I am Corporate Secretary of MINACT, Inc., a Mississippi based corporation that currently operates four job corps centers. These centers are located in Knoxville (Tennessee), Batesville (Mississippi), St. Louis and Excelsior Springs, Missouri. Prior to my joining MINACT, Inc., I spent forty-one and one-half years with the Mississippi Employment Security Commission and at my retirement was Executive Director of that organization. During my tenure with the Mississippi Employment Security Commission, I had an opportunity to be involved in job corps operations since its inception in 1965. Before entering college and immediately after graduation from high school in 1937, I entered the Civilian Conservation Corps (CCC) which in reality is the forerunner of the job corps program. For these reasons I feel I am eminently qualified to present testimony to this Committee concerning the effectiveness and needs of the Job Corps program.

There is no question that we need to maintain a budget of at least 618 million dollars for FY 85 since there are currently thousands of youth who are waiting to take advantage of the excellent training they can receive through this program. The unemployment statistics for young people, particularly minority youth, vividly points up this need. Mississippi youth have always taken advantage of the Job Corps program in relatively large numbers. Through my work with the Employment Security Commission, I was able to see the excellent training that is taking place throughout the United States. In fact, for a number of years Mississippi had a one of the highest placement rate of returning job corps enrollees of any state even during the current tough economic times, the rate has not shown any substantial drop. For this reason, I consider Job Corps to be the most successful training program currently being operated.

A decrease in funding for this program would cause a farther deterioration in the training facilities, many of which are in dire need of renovation and maintenance. You are aware of course, that the majority of the centers were built for some other purpose than Job Corps activities and were renovated to accommodate the program. Many of these facilities are old and require a great deal of maintenance and rehabilitation. Many are badly in need of capital improvements to bring them or keep them up to the minimum standards that are required to train young people.

Although placement has been good to excellent historically, I am concerned about equipment for the vocational skills that are currently being offered which, in many instances, has not kept pace with "the state of the art." It is imperative that in order for the job corps graduates to remain competitive in the workforce that they must be trained on the latest equipment being used by industry throughout the country in the particular occupation for which they receive training. Many of the centers need funds to upgrade equipment so that the young people can be adequately trained to meet the needs of the labor force.

Contractors (operators) are continually striving to improve the basic education programs for the enrollees and we consider this the "cornerstone" of the total program. Without proper basic education, it is almost impossible for a young person to adequately absorb the vocational/technical training being offered. New techniques for improving the basic education instruction are continually being developed and it is imperative that the job corps stay abreast and provide the latest techniques and equipment for this important phase of the youth's training. In an attempt to keep pace with the recent technological trend which currently exist in our society, there is an urgent need to implement Computer-Based Instruction in the Job Corps training programs.

Computer Based Instruction is one of the newer trends to improve educational effectiveness in the classroom. It enhances the ability of individual teachers to reach students while, at the same time reduce drudgery of repetitive teaching on the enrollees. Moreover, Computer Based Education greatly enhances the overall learning process.

Residential living quarters are in many instances badly in need of capital improvements and funds have not been available in the last several years to provide the renovations which are needed. We at MINACT, Inc. consider the residential living component an integral part of the training since many of the enrollees come from environments that do not adequately instill in them the values that society will demand of them when they become workers in the industrial complex.

Due to the unsettled situation throughout the world, we are convinced that pre-military training is a strong plus for job corps enrollees . We have this training at the St. Louis Center and it has proven to be very popular with the corpsmembers. It has brought a strengthening of support from the community relations council and the general public, who are highly complimentary concerning the pride and patriotism that is being generated through the pre-military program.

The Advanced Career Training program needs to be reinstituted. Many corpsmembers have benefited from this program in the past and many more can still benefit from such a program. Through the Advanced Training Program, several students have completed advanced level degrees, and have done exceptionally well in their areas of expertise. We hasten to point out that funding for this component should be separate and apart from the regular program.

We feel that the awarding of contracts to private industry for the operation of the job corps centers is the most effective way to operate and we encourage expansion and continuation of this method for ensuring the most cost-effective and best training available for our young people. In our opinion this is in keeping with the recently enacted Job Corps Training Partnership Act that encourages more involement in the private sector in the federally supported training programs. We at MINACT, Inc. are extremely proud of the success we have had in training the young people assigned to the centers which we operate and particularly in the records they have achieved.

The plea today, Mr. Chairman, is that sufficient funds be provided to improve upon the operations that are currently being carried out and that the regional and national staff be strengthened in order to assure that each contractor carries out the terms of his contract that will provide the maximum benefits to the youth of this country.

We appreciate most sincerely the opportunity of presenting this testimony and will be glad to answer any questions.

STATEMENT OF STEVEN DARDEN, CHAIRMAN, AFFILITATION OF ARIZONA INDIAN CENTERS, INC.

My name is Steve Darden, Chairman of the Board of Directors for the Affiliation of Arizona Indian Centers, Inc. My testimony is presented on behalf of the Affiliation. In recent months, it has been reported that there is an improving economy nationwide. The unemployment rate has dipped, the average salary has increased and business is on the upswing. What effect has this news had on the Arizona Indian worker? The 1980, U.S. Census stated that Indians and Native Americans numbered 152,745 in Arizona. A report, "INDIAN SERVICE POPULATION AND LABOR FORCE ESTIMATES," issued by the Bureau of Indian Affairs in January 1983, stated that the Arizona Indian population had risen to 154,818. The report also had bad news for Indians wanting to work.

BIA January 1983 Estimates

Total Indian Workers available for work (Indians 16 to 65 years of age, not in school or otherwise unavailable for work)		69,509
Total Arizona Indians employed		28,290
Total earning $7,000 a year or more	18,125	
Total earning less than $7,000	10,165	

In January, 1983, the BIA estimated that 59% of those Arizona Indians available for work were not employed. 75% of those available for work were either not employed or underemployed and had earnings of less than $7,000 per year.

Since January, 1983, the economic situation for Arizona Indian workers has not improved along with that of the general public for two reasons:

1. Since 1980 most federal programs, that directly serve Indian people, have been eliminated or drastically reduced.

2. The improving economic conditions have not reached Indian workers and their families because in Arizona almost all Indians live in rural areas outside the metropolitan areas of Phoenix and Tucson and in the metropolitan areas Indians are still plagued with underdeveloped skills and for the most part do not successfully compete for jobs. In Arizona, Indians live, for the most part, in rural counties where job opportunities have not seen an increase like those in the metro areas.

The following is a listing put out by the Arizona Department of Economic Security Job Bank. The list was prepared for the week of February 6, 1984 with the following number of job openings in each county:

Maricopa (Phoenix)	1,860	Mohave	2
Pima (Tucson)	411	Santa Cruz	2
Pinal	19	Gila	1
Cochise	7	Graham	1
Yavapai	5	Navajo	4
Coconino	3	LaPaz	0
Yuma	3	Apache	0

CETA and JTPA programs have helped improve the economic conditions of Arizona Indian families and enabled Indian workers to successfully compete in the job market, but current amounts allocated to Indian programs under Title IV of JTPA are not sufficient to meet current needs or to impact significantly upon the problems facing Indian workers in Arizona in todays high-tech job market. Therefore, it is respectfully recommended that allocations for Indian JTPA programs be increased to provide opportunities for Indian workers to train for job opportunities that are becoming available in our improving economy.

STATEMENT OF PAUL S. EGAN, DEPUTY DIRECTOR, NATIONAL LEGISLATIVE COMMISSION, AND JAMES G. BOURIE, DIRECTOR, NATIONAL ECONOMIC COMMISSION, THE AMERICAN LEGION

The American Legion thanks you for allowing us this opportunity to present its views on the proposed FY 1985 appropriation for the Department of Labor, specifically the Office of the Assistant Secretary for Veterans Employment and Training. Pertinent resolutions adopted by The American Legion are attached, with the request that they be made part of the record.

The Office of the Assistant Secretary for Veterans Employment and Training (OASVET) is, by law, the primary deliverer of programs and services to veterans in need of employment/training assistance. It is a relatively new department component, previous veterans programs having been scattered among several divisions. By comparison, it also is one of the smallest divisions in terms of staff and resources.

The total staffing of the OASVET for FY 85 is approximately 302 personnel: 37 at the national office; nine Regional Directors of Veterans Employment and Training; 52 State Directors of Veterans Employment and Training; 52 secretaries; and 152 Assistant State Directors for Veterans Employment and Training. To support this number, $12.872 million is requested, to include $535,000 for travel funds. This last figure represents the same amount authorized during fiscal years 1983 and 1984, but overall, the request represents a modest $872,000 gain in salary and expenses over the current fiscal year's figure of $12 million.

In our estimation, this represents a "barebones" budget with little or no growth. This is especially significant because veterans unemployment rates have not begun to stabilize for younger and Vietnam era veterans. Indeed, those groups still have rates higher than the national average and higher than their non-veteran peers. We thus believe that the proposed budget for the OASVET to only be adequate, and that any reduction of resources will severely reduce the OASVET's ability to provide employment/training services and programs to veterans. While The American Legion commends both Secretary Donovan and Assistant Secretary Plowden for their genuine concern and aggressive pursuit of veterans employment/training issues, we are all too aware of the critical balance that exists between services and funding.

Mr. Chairman, we must, however, voice our objection to the proposed loss of two (2) Regional Directors of Veterans Employment and Training and two (2) accompanying secretarial positions. We understand that all department programs are required to reduce their field programs, but we don't believe that,under the circumstances of high veteran unemployment, this is the best time to reduce the Veterans Employment and Training Service. Regional Directors of Veterans Employment and Training are key field staff to oversee and coordinate the activities of the State Directors of Veterans Employment and Training and serve as a valuable conduit between the states they serve and the national office.

The "front line" employment/training service to veterans remain the local veterans employment representatives and Disabled Veterans Outreach Program specialists stationed in local Job Service offices and elsewhere. They are state employees whose primary function is to serve eligible veterans. There are approximately 1,580 fulltime local veterans employment representatives (LVERs) and 1,077 Disabled Veterans Outreach Program (DVOP) specialists. For fiscal 1985, the amount requested for LVERs shows an increase from $46.2 million to $50.1 million. However, funds for DVOP services will be reduced by $3.4 million to $59.2 million due to shifting veteran demographics and federal law (38 USC 2003A). Again, the proposals are only adequate and present no significant growth for either program. One point that needs to be made is that funding for these programs comes from the Federal Unemployment Trust Account, long a source of contention by the Job Service.

Mr. Chairman, there would be no point to having an Office of the Assistant Secretary for Veterans Employment and Training if there were no veterans employment/training programs. The American Legion led the way to establish the first-ever national veterans program with Title IV-C of the Job Training Partnership Act. And we are the first to state that the amount allocated to IV-C is far below expectations. In FY 84, only $9.7 million was appropriated, and in FY 85, $8.846 million is proposed. With such a meager amount, most states will be allotted less than the originally projected minimum of $50,000 per state for FY 85 to address veterans employment/training needs. The American Legion has received numerous inquiries and complaints from concerned veteran advocates from across the country wondering how a responsive veterans employment/training program can be supported on $50,000 or less. We realize that Title IV-C funding is predicated on formula. However, we realize also the impact of veterans unemployment rates and of the vast potential Title IV-C programs can mean.

To conclude, Mr. Chairman, The American Legion's assessment of the FY 85 proposed budget for the Office of the Assistant Secretary for Veterans Employment and Training is adequate, except for Title IV-C funding. We further feel that any reductions will have a negative impact on veterans employment/training services during a time of high veterans unemployment.

SIXTY-FIFTH ANNUAL NATIONAL CONVENTION
OF
THE AMERICAN LEGION
AUGUST 19-25, 1983
SEATTLE, WASHINGTON

RESOLUTION NO. : 165

COMMITTEE : ECONOMICS

SUBJECT : FULL FUNDING FOR THE OFFICE OF THE ASSISTANT SECRETARY FOR VETERANS EMPLOYMENT AND TRAINING

WHEREAS, PL 96-466 established the Office of Assistant Secretary for Veterans Employment and Training to coordinate and direct all veterans employment/training activities within the Department of Labor; and

WHEREAS, In order to fully implement those pertinent sections of title 38, USC, as regard veteran employment matters, the Assistant Secretary for Veterans Employment and Training must be fully funded; and

WHEREAS, Underfunding of the Office of Assistant Secretary for Veterans Employment and Training will have a negative impact on the employment/training delivery services to all veterans, especially those of the Vietnam era; now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Seattle, Washington, August 23, 24, 25, 1983, that the office of the Assistant Secretary for Veterans Employment and Training, U.S. Department of Labor, be fully funded to carry out its mission as prescribed by law and regulation.

RESOLUTION NO. : 245

COMMITTEE : ECONOMICS

SUBJECT : VETERANS EMPLOYMENT TRAINING PROGRAMS

WHEREAS, Veterans of all eras are experiencing unemployment and underemployment problems of significant proportions nationwide; and

WHEREAS, Congress in enacting the Job Training Partnership Act at Title IV-C provides for a National Veterans Program; and

WHEREAS, Older generations of veterans are also in need of employment/training programs that address their economic needs and reflect their years of economic contribution and talents; now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Seattle, Washington, August 23, 24, 25, 1983, that The American Legion urge Congress to provide for veterans of all eras who are in need of employment/training assistance in all proposed federally funded training programs.

RESOLUTION NO. : 407

COMMITTEE : ECONOMICS

SUBJECT : SEEK INCREASE IN STAFF FOR STATE EMPLOYMENT OFFICES

WHEREAS, The Employment Service has been in existence since 1933 to provide free job assistance to unemployed persons; and

WHEREAS, One of the primary functions of the Employment Service is to provide veterans with an effective priority service; and

WHEREAS, The Employment Service budget has been severely curtailed, in spite of an increase in the size of the labor market and a substantial increase in the use of the Employment Service by employers and unemployed persons during the past several years; and

WHEREAS, This huge increase in services requires additional staff and offices throughout the United States in the Employment Services to maintain and improve employment services for veterans and all other applicants, now therefore be it

RESOLVED, By The American Legion in National Convention assembled in Seattle, Washington, August 23, 24, 25, 1983, that Congress and the Department of Labor be requested to support an increase in positions and funding therefor in the State Employment Services so that an effective employment service, including employment services to veterans, can be maintained.

NATIONAL EXECUTIVE COMMITTEE
OF THE AMERICAN LEGION
INDIANAPOLIS, INDIANA

OCTOBER 12-13, 1983

NO.: 17

COMMITTEE: ECONOMICS

SUBJECT: SEEK INCREASE IN FUNDING FOR VETERANS PROGRAMS UNDER THE JOB TRAINING PARTNERSHIP ACT

WHEREAS, Congress in 1983 replaced the Comprehensive Employment and Training Act of 1973 with the Job Training Partnership Act as this country's federally funded national employment/training program; and

WHEREAS, Under Title IV, Part C of this Act, there is established a National Veterans Program for Vietnam, disabled, and recently separated veterans; and

WHEREAS, Under Title IV formula only $9.3 million is available for fiscal 1983 to address the consistently high and pressing unemployment programs of such veterans; and

WHEREAS, Funding levels mut be adequate to meet program demands, so as to resolve the long-term employment/training problems of such veterans; now therefore be it

RESOLVED, By the National Executive Committee of The American Legion in regular session assembled in Indianapolis, Indiana, on October 12-13, 1983, that The American Legion seek to increase funding for veterans programs under Title IV-C of the Job Training Partnership Act.

STATEMENT OF RUTH FOSSEDAL, PRESIDENT, DISPLACED HOMEMAKERS NETWORK, INC.

The Displaced Homemakers Network is pleased to submit the following testimony to the Labor-HHS-Education Appropriation Subcommittee.

The Displaced Homemakers Network, Inc., organized in 1980, is a national non-profit organization of over 4,000 displaced homemakers, displaced homemaker services providers, and other supporters. The organization's purposes are to work toward the economic self-sufficiency through employment of displaced homemakers, and to provide resource materials for and communication linkage among programs and members.

Job preparation and training is essential for millions of displaced homemakers who find themselves forced into the labor market in order to survive. These are women--generally over the age of 35, and most often older--who have remained at home for a number of years to care for their families and then lose their means of support through death of the spouse, separation, divorce, or ineligibility or pending disqualification for public assistance. They are too young to collect Social Security, do not qualify for unemployment insurance, and are unable to collect under a husband's pension plan. They cope with personal, family and economic crises at the same time. In their shift from dependency to self-sufficiency they must upgrade their skills and acquire training to prepare them for gainful employment.

By conservative estimate, there are over four million displaced homemakers in the nation. Although their personal situations vary depending upon their age and family status, the majority of these women have similar basic needs. These women need jobs in order to survive. To enable them to get these jobs they require transitional support services and training that will make them marketable in an increasingly competitive job market. Younger displaced homemakers often have children to support. The needs and special problems of single parent families are many. More often than not the economic situation for the female single parent is bleak, particularly if she is having to enter the labor market for the first time. For women over 40, who make up 75% of the displaced homemakers in our nation, the situation is even worse.

The term displaced homemaker truly describes these women who are in transition. After many years of unpaid labor in the home caring for family members, they suddenly have lost their jobs. Even for the displaced homemaker who successfully moves from the home to paid employment, the prospect of poverty is a reality not to be ignored unless she can be given the training to access jobs that pay more than minimum wage. Three out of five working women earn less than $10,000 per year and one in three less than $7,000. Sixty-two percent of all service and retail workers are female and almost 80 percent of all clerical postions are held by women. These jobs often provide low wages, few if any benefits, and limited upward mobility. And today we know that over 50 percent of all women over 65 have an income under $4,757 per year.

No wonder two out of three adults who fit the federal definition of poverty are women--many of them displaced homemakers. And far too few of us realize that 85 percent of all married people will one day be "single" due to death or divorce. In fact, 85 percent of all surviving spouses are women.

Displaced homemaker programs across the nation seek to address the problems of employment for displaced homemakers. Services include career exploration as well as critical personal and vocational counseling. Participants are introduced to many occupations once considered to be "men's work" but which provide good wages and advancement opportunities.

Displaced homemaker centers across the nation have been successfully addressing this problem since the mid-seventies. Through these centers thousands of women have received crucial personal and vocational counseling, pre-employment services, as well as training and job placement. Because of their very special needs these services are seldom available to them through other organizations. These centers provide the critical support services required to allow displaced homemakers to remain in traditional training programs. Unfortunately, because of the dual discrimination of ageism and sexism, large numbers of displaced homemakers find themselves selected out of the more traditional programs. The special displaced homemaker centers have proven themselves to be most effective agents for bridging the gaps and opening new doors for their clients.

It would seem that displaced homemakers are a population that the Jobs Training Partnership Act is designed to serve, "to afford job training to . . . individuals facing serious barriers to employment, who are in special need of such training to obtain productive employment." The Displaced Homemakers Network has participated in workshops on JTPA across the country and has conducted a survey of displaced homemaker programs. Our investigation indicates that displaced homemaker programs are encountering great difficulty in their efforts to obtain JTPA training funds. Programs report that Private Industry Councils are not accepting applications from displaced homemakers programs, do not understand the employment needs of older women and are aware of the financial and support services needs of women who head households while in training.

Thus, it seems when displaced homemakers ceased to be a population that had to be served under employment and training legislation, displaced homemakers ceased to be served. We strongly encourage future funding for employment and training programs require that displaced homemakers be served.

At the national level the Displaced Homemakers Network is the only national organization serving the nation's four million displaced homemakers. The Network provides technical assistance to more than 300 programs across the country serving displaced homemakers, provides public information on displaced homemakers' concerns, monitors public policies which impact displaced homemakers, and works at the local and state levels to affect the futures of displaced homemakers across the U.S.

The Network maintains a directory of displaced homemaker programs across the country which is essential in responding to the requests we receive from over 200 displaced homemakers each month regarding local services and job opportunities. When written articles appear we often receive over 300 calls and letters during one week. We are well aware of the needs of displaced homemakers and the programs that serve them. Up-dating this Directory, the Network maintains a list of current programs and services and keeps track as programs and services change.

The Network also publishes a quarterly newsletter which is distributed to more than 4,000 individuals and organizations. This has proven to be an effective mechanism for providing information about JTPA and other relevant legislative and programmatic issues of concern to our members.

The Network currently has a staff of four and an operating budget of approximately $160,000 for a nine month period. Clearly we face severe limitations given the size of our staff and budget and the size and needs of the population we seek to serve. The problems of displaced homemakers are not confined to one area or region of the country. Nor is the occurrence of displacement likely to diminish. It is estimated that 40% of marriages begun now will end in divorce. The life expectancy of women has increased, with women over 60 twice as likely to be impoverished as their male counterparts.

The issue of displaced homemakers is a national one and requires national attention. Congressional efforts last year assured continuation of the National Network for 21 month period only. Appropriated funds must be designated to support the Displaced Homemakers Network on an on-going basis. The changes in funding levels and the uncertainty of Network funding in the past has inhibited the Network's fully effective operation and long term planning.

The Network and its member programs have been working for more than six years on strategies and employment and training related services to assist displaced homemakers acheive economic self-sufficiency. Our understanding of the population offers a cost effective resource in the design and delivery of employment and training programs to those for whom the legislation was enacted. Much has been accomplished but much remains to be done. In just a few short years displaced homemakers have learned to value their homemaking skills and their life experiences. This committee has shown a recognition and interest in this vast human resource. We look forward to your leadership in advancing legislation which will fill the gaps and allow displaced homemakers to find a place as productive members of our national workforce.

Statement of the National Crushed Stone Association

The National Crushed Stone Association wishes to correct the Subcommittee Record concerning a statement made by the Assistant Secretary of Labor for Mine Safety and Health, David A. Zegeer. Following Mr. Zegeer's formal statement at the Subcommittee Hearing on March 8, 1984, Subcommittee Chairman Weicker asked him the following question:

> "Last year, miners in sand, gravel and surface stone, surface clay, colloidal phosphates and surface limestone were exempted from training requirements. How have injury and fatality rates for those categories changed since this amendment was adopted?"

Mr. Zegeer's answer included the following statement:

> "Up to the first nine months of last year, that group had a frequency rate of .05 whereas for the same period, the coal industry had a lower rate of .04 which says they do have their share of fatalities."

Mr. Zegeer's answer is not correct. The combined fatal incidence rate for stone, sand and gravel industries, based upon official MSHA statistics for the first nine months of last year is not .05. The correct incidence rate is .03 which is a 25% lower incidence rate than that of coal and also 25% lower than that of other metal and nonmetal mining for the same nine month period.

Further, Mr. Zegeer's answer dealt only with fatality rates. A comparison of Nonfatal Disabling Injury Rates for last year for sand, gravel and stone compared to the coal industry is

Sand Gravel and Stone	2.54
Coal Industry	5.63

Nonfatal disabling injuries (indicated as NFDL in table A below) are defined by MSHA as nonfatal injury occurrences with days lost that result in days away from work or days of restricted work activity.

These rates are both computed using MSHA provided statistics applied to the standard incidence rate formula used by MSHA. The formula is:

$$\frac{\text{number of occurrences} \times 200{,}000}{\text{total manhours worked}} = \text{incidence rate}$$

For the information and convenience of the subcommittee table A is provided. The column marked NDL means, according to MSHA, No Days Lost. These are injuries resulting only in loss of consciousness or medical treatment other than first aid.

BASED ON MSHA PUBLICATION "MINE INJURY AND WORKTIME, QUARTERLY"
January - September 1983

1983 COMPARISON OF COAL MINING INCIDENCE RATES COMPARED WITH STONE, SAND & GRAVEL

	FATAL	RATE	NFDL	RATE	NDL	RATE	ALL OCCURENCES	ALL INCIDENCE RATES	TOTAL MANHOURS
Coal	52	.04	6,925	5.63	1,763	1.43	8,740	7.11	245,814,809
Stone, Sand & Gravel	22	.03	1,825	2.54	886	1.23	2,733	3.79	143,945,484

TABLE A

To further answer the question posed to Mr. Zegeer by Chairman Weicker, NCSA presents the following additional facts

1. Since 1979 when the Appropriations Committee first enacted the training exemption, stone, sand and gravel fatal incidence rates have been reduced by the following percentages:

stone only	- 50% reduction
sand & gravel only	- 30% reduction
combined stone, sand and gravel	- 37% reduction

These reductions are based on comparisons of MSHA official statistics for 1979, the year in which the appropriations bills set the limitation on MSHA's authority, and the first nine months of 1983, the latest statistics distributed by MSHA to mining industries.

2. Nonfatal disabling injury incidence rates for these two industry groups have also shown dramatic decreases from 1979 to 1983.

stone only	- 39% decrease
sand & gravel only	- 33% decrease
combined stone, sand & gravel	- 38% decrease

3. Mr. Zegeer did state during his appearance before the subcommittee on March 8, 1984 that many stone quarries and sand and gravel pits continue to operate their own safety training programs. NCSA believes that most of them do so. NCSA has actively encouraged safety training. By not being required to conform training programs to rigid regulatory specifications based upon those safety considerations for all types of

mining, stone, sand and gravel operators have the freedom to address only those safety and health training considerations which directly relate to their own personnel and the specific hazards which exist at their facilities.

NCSA strongly urges that the prohibition of the use of appropriated funds by MSHA to enforce the training provisions of the 1977 Mine Safety and Health Act on surface stone, sand and gravel, clay and colloidal phosphate mines be continued for fiscal year 1985. During the four years this limitation on MSHA has been in effect, the safety and health of our workers has not been affected detrimentally. Rather, our injury and fatality rates show dramatic reductions.

STATEMENT OF KATHERINE S. McCARTER, ASSOCIATE EXECUTIVE DIRECTOR, AMERICAN PUBLIC HEALTH ASSOCIATION

Senator WEICKER [presiding]. The next witness to appear before the committee is Katherine McCarter, associate director of the American Public Health Association.

Ms. McCARTER. Thank you, Senator. We are happy to be here before you today.

APHA is a multidisciplinary professional society representing a combined national and affiliate membership of over 50,000 public health professionals and community health leaders.

I have tried to focus on programs of the Public Health Services which we believe have been shown to prevent disease and suffering and which comprise the public health infrastructure in this country.

The general theory behind the development of these programs, to immunization and TB control to internal health programs, we feel is appropriate, effective, and relatively inexpensive in the long run.

We, therefore, are very concerned about the abandonment of some of those goals which we feel have been occurring as a result of cuts that have been enacted and some of the cuts that are being preserved.

Taking a look at the Centers for Disease Control, I am going to take a look at that. The Immunization Program, as you know, provides immunizations for children with measles, mumps, rubella, polio, and other diseases.

Vaccine prices have risen over 50 percent in the last 3 years, while the price of DPT vaccinations has increased over 200 percent. We, therefore, recommend that the Immunization Program be funded at $54 million, which would allow the program to maintain its current levels. It would also include the $2 million rubella initiative which the President has recommended and, in addition, a $4 million program for the States to help pay for key vaccinations. Prices have risen so dramatically in the last several years. We feel this is necessary.

In the infectious disease area, we support recommendations that the TB project grants be funded at $12 million.

As you are no doubt aware, Senator, the new cases of tuberculosis have risen over the last several years, and most of those cases are centered in urban areas such as low income and minority persons. Therefore, the need for the project grants is to target money for those States and those localities and cities with the greatest need and in populations with the greatest need.

We are supporting the administration's request of $55 million for the Venereal Disease Program, but we recognize that in future years there will be a much greater need for additional funding in the VD Program because we are experiencing an epidemic in this country with venereal disease, and we anticipate that there will be much greater support needed in the future.

In the epidemic services area, we urge you to reject the administration's request to save $2 million from charging user fees for CDC's diagnostic laboratory service. These are services which are provided to the States for laboratory testing because the States either lack the skills to do the tests themselves or because the specimens are so unusual that the States are unable to actually look at them properly.

By charging user fees, we are afraid that the flow of information to CDC about disease conditions in this country would be inhibited and that higher charges would be charged to patients.

CDC's own Director, James Mason, admitted under congressional testimony, under congressional questioning, that these fees were counterproductive, and we do hope the Congress will reject them as well.

The American Public Health Association is very, very supportive of the prevention block grant, which, as you know, has a number of categorical programs, including programs related to fluoridation, rat control, hypertension. All these programs were combined in a block grant in 1981.

The funding level which is currently being recommended by the administration is still well below the 1981 levels for those programs, and we are urging that the block grant be funded at a minimum of $98 million and up to $115 million, which would represent—I think the Association of State Health Officers will probably talk about this more—but approximately 50 cents per capita for these programs.

We also believe that mandatory reporting requirements should be added to the block grants in order to allow us to understand better how the funds are being used and how the block grant is working.

Along those same lines, one of the priorities of HHA is information and data about health status. We are very concerned that the National Center for Health Statistics funds are being reduced by $4 million.

One of the troubling aspects of this is that it would cause a delay in the startup of the HANES II survey, which is the nutritional survey, and a survey which the President's own Commission on Hunger indicated that they were waiting for that data in order to be able to know the nutritional status of persons in this country. We would have to wait longer for that if the President's request were adhered to.

So we would urge that that reduction be rejected as well.

HHA supports the Family Planning Program. We would hope that it would be continued in its categorical program and transferred back to the professional control that Congress has already mandated. We hope that it would be funded at a fully authorized level at $170 million, and I am sure there will be witnesses that will talk in detail about it.

Finally, I would like to end with the MCH and primary care block grants, which we are also very concerned with. We oppose the addition of new programs to the primary care block grant, family planning, migrant health, and black lung programs.

We support the MCH Block Grant Program and hope that it could be funded to its fully authorized level, and we understand that the House is currently considering authorizing $499 million as a committee recommendation. $483 million would be adequate.

There are other programs within my testimony that we have dealt with, and I will not go into all of those now, but I would be happy to answer any questions.

PREPARED STATEMENT

Senator WEICKER. I have no questions. Your statement in its entirety will be included in the record at this time.

[The statement follows:]

STATEMENT OF KATHERINE S. MCCARTER

Mr. Chairman, I am Katherine S. McCarter, Associate Executive Director of the American Public Health Association (APHA). Thank you for providing the Association this opportunity to present its views.

APHA is a multi-disciplinary professional society representing a combined national and affiliate membership of over 50,000 public health professionals and community health leaders.

Over the last two decades many federal programs have been developed to preserve the public's health and to meet special health needs. The general theory behind the development of these programs--from immunizations and tuberculosis control to maternal and child health programs--was that disease prevention and early treatment is appropriate, effective and relatively inexpensive in the long run. It is therefore difficult to understand why these programs, which contribute to the public health in a cost-effective manner have been singled out for negative attention in recent budget requests.

We believe that the Administration's FY85 budget proposal for health and human services will undermine the health of our citizens and of our health care system. Those of us involved in the administration and delivery of health services are troubled by the abandonment of important public health goals as a result of the cuts already enacted and the levels now being proposed.

My testimony will focus on certain programs of the Public Health Service which we believe have been shown to prevent disease and suffering and which comprise the public health infrastructure in this country.

Centers for Disease Control

The Centers for Disease Control (CDC), charged with protecting the public health of the nation, provide leadership and direction in the prevention and control of diseases and other preventable conditions.

APHA's recommendation of a 10% increase in 1985 to $417 mil for CDC would preserve important public health programs such as those dealing with childhood immunizations, tuberculosis control, prevention programs at the state and local level, and research and surveillance related to newly emerging health problems such as Acquired Immune Deficiency Syndrome.

Immunizations

Vaccine prices have risen generally over 50% in the last three years while DPT prices have increased over 200%. A funding level of $54 mil would assist state and local health agencies in purchasing vaccine and conducting immunization programs against childhood diseases such as measles, mumps, rubella, polio and other diseases. We support the Administration's request for a $2 mil rubella initiative, and are recommending an additional $4 mil for a new program to allow the federal government to share in the costs of purchasing DPT vaccine.

Infectious Diseases

The incidence of new cases of tuberculosis is rising--with concentrations found in major urban areas among low-income, minority and refugee populations. The Administration has requested no funds for the TB project grants which were created in 1982. We recommend $12 mil for the TB project grants in order to allow funds to be targeted to populations and areas of greatest need.

Acquired Immune Deficiency Syndrome (AIDS), which is a collapse of the body's immune system, has an alarmingly high fatality rate of nearly 80%. The number of reported AIDS cases has nearly doubled every six months. APHA supports the Administration's request for AIDS funding and recognizes that additional funds may be needed in the future to explore new areas of research and for public education.

Venereal Disease

We support the Administration's request of $55 mil for 1985 for the venereal disease program. In future years, however, significantly greater resources need to be directed to venereal disease prevention and control. Statistics show that one in four Americans between the ages of 15 to 55 is affected by the epidemic of venereal disease. This year more babies will die from VD than the total number of deaths from Toxic Shock Syndrome, Legionnaires Disease and AIDS combined.

Occupational Health

APHA opposes the elimination of training for occupational health professionals and requests restoration of $9 mil for that program in the National Institute of Occupational Safety and Health.

Epidemic Services

APHA rejects the savings of $2 mil resulting from the charging of user fees for CDC's diagnostic laboratory services. Charging for services which appropriately are the responsiblity of the federal government will result in higher charges to patients and will inhibit the flow of information necessary to control and prevent disease. CDC's Director, Dr. James Mason, recently admitted under congressional questioning that user fees were "counter productive."

Chronic and Environmental Diseases

Activities conducted by CDC provide a comprehensive public health approach to chronic and environmental conditions such as diabetes, birth defects, toxic waste spills, radiation releases and malnutrition. APHA's recommendation of $29 mil would allow CDC to continue its current level of effort.

Prevention Block Grant

APHA recommends that the administration of the Prevention Block Grant be retained under the professional supervision of CDC. The $89.1 mil recommended by the Administration for the block grant is well below the 1981 level of $93.2 mil for the programs which comprise the Prevention Block Grant.

In Massachusetts alone, federal monies for hypertension programs (which were included in the block grant) have been cut over 40 percent in recent years, and only 12 of the over 59 areas in Massachusetts considered high risk for hypertension have been able to establish programs.

APHA urges that this Block grant be funded at a minimum of $96 mil. While this will not keep pace with inflation, it would provide additional support for hypertension, home health services, emergency medical services, rodent control, fluoridation, health incentive grants rape services and health education risk reduction programs.

In addition, APHA believes that mandatory reporting requirements should be added to insure accountability and a better understanding of how the block grant is working.

Office of the Assistant Secretary for Health

Health Statistics

APHA is extremely concerned that proposed cut for the National Centers for Health Statistics (NCHS) will cause essential health data to be delayed to the point where there is real damage to knowledge about health. The $4 mil reduction for NCHS will mean that several multi-year health studies will have their start-up cycles pushed back by at least a year.

Of particular concern will be the one year delay in the cycle of the National Health and Nutrition Examination Survey (HANES). Ironically, the President's task force dealing with hunger reported that HANES serves as one of the major foundations for any statement about the nutritional status of Americans, but that the lack of up-to-date data from the study "has made it impossible to assess whether the current nutritional status of the population has worsened over the last few years."

Health Promotion

APHA supports the Presidents request of $4 mil for the Office of Disease Prevention and Health Promotion (ODPHP). The Office helps to promote health and prevent disease through leadership, coordination and support for Department strategies and programs in prevention. One of the ODPHP's most important roles is to implement the 1990 Prevention Objectives and to monitor the nation's progress toward them.

Family Planning

The Association opposes the transfer of the family planning program to the Primary Care Block Grant, and urges that the management of this program be returned to HRSA as mandated by Congress. The Title X Family Planning Program is cost effective. For every dollar spent on teenage family planning services, $3 are saved in health and welfare costs. In 1981, the program served 4.6 million low and marginal income women received services, including 1.5 million teenagers under age 20. We urge that Title X be funded at its authorized level of $170 mil.

Health Resources and Services Administration

MCH and Primary Care Block Grant

The Association opposes the transfer of the administration of the block grants from the professional control of the Public Health Service to the political realm of the Assistant Secretary for Health. In addition, we oppose the addition of family planning, migrant health and black lung clinic programs to the Primary Care Block Grant.

The House is currently considering raising the MCH Block grant authorization to $499 mil. APHA urges that this block be funded at this level if authorized, or as a minimum, the current House recommended level of $483 mil.

Health Planning

Over the past several years, approximately $1 billion out of $5 billion worth of proposed hospital projects have been turned down and another $1 billion owrth of projects were not even submitted for certificate-of-need review because hospitals anticipated that they would not be approved. If the health planning program were eliminated, a 50% increase in capital construction could be anticipated in the next four years. We recommend $80 mil for health planning in 1985.

In conclusion, let me once again emphasize the cost-effectiveness of the above mentioned programs. Many have prevented the need for expensive long-term hospital and custodial care. It is penny wise and pound foolish to underfund expenditures for prevention and early treatment.

Thank you. I would be pleased to answer any questions.

STATEMENT OF ROBERTA BALSTAD MILLER, EXECUTIVE DIRECTOR OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Senator WEICKER. The next witness is Roberta Miller, the executive director of the Consortium of Social Science Associations.

Ms. MILLER. Senator Weicker.

Senator WEICKER. Please proceed.

Ms. MILLER. The Consortium of Social Sciences represents 34 disciplinary associations, a list of COSSA members, affiliates, and contributors.

I am here to testify today on the fiscal 1985 budget of the Office of the Assistant Secretary for Planning and Evaluation, also known as ASPE, in the Department of Health and Human Services.

The administration is requesting a budget for this Department for fiscal 1985 of $8 million. That is $2 million below the fiscal 1984 level, which was $4.7 million below the 1983 level, and the current proposal is $16 million below the 1980 level.

Basically, what has been happening is that the administration has been chipping away in small amounts at this budget over the past 5 years. At the present time, the proposed budget for ASPE will allow the office only to continue funding current obligations. It will not allow it to undertake any new research.

The Consortium for Social Science Associations is requesting the Senate Appropriations Committee to reverse this trend. Basically, we are requesting a budget for ASPE of $10 million, which is the fiscal 1984 level, maintaining that same level in 1985.

There are several reasons for this. First, and I think foremost, ASPE funds long-range studies that are central to HHS responsibility. They fund additional studies, such as understanding the causes of poverty and the economic consequences of dependency. They fund studies on public and private pension systems and their impact on the economic status of the aged.

They fund longitudinal data collection on family change and infant change over time so that we know something about who is on welfare for what reasons and for how long. It permits us to make some educated guesses as to how long the current people will be on welfare, how long they will continue to remain, so our second reason for funding ASPE at the current level is that ASPE has a very good track record. The staff is very good and very qualified. The research has not been criticized. The topics it supports are highly germane to HHS responsibility.

There is, in short, no reason to cut the ASPE research budget on the basis of what it has done.

Finally, I would like to discuss some issues specifically raised by the Grace Commission report, which is recommending that the ASPE budget gradually be phased out and the research responsibilities that ASPE has be transferred to the operating divisions at HHS.

These divisions are the Public Health Service, Social Security Administration, the Clinical Health Care Financing, and the Office of Human Development Services. The only problem with this is that the operating divisions at ASPE have program responsibilities.

They are not basically research facilities. They deal with short-term agendas, and the research they fund generally is on a short-term basis. They don't fund the kinds of projects that can provide results that come after years and years of study.

In addition, ASPE funds research on topics that cut across the responsibilities of the various operating divisions. The research that ASPE funds now would not be done if all these research functions were transferred into the operating divisions.

In conclusion, I would like to point out that ASPE has done good research. It has done important and useful research and that the information available to HHS officials and the assets would be greatly diminished if ASPE's budget decline is allowed to continue the way it has done in the past several years.

I urge the Senate Appropriations Committee to fund it at $10 million further than the $8 million requested.

PREPARED STATEMENT

Senator WEICKER. Thank you very much. It is a very precise statement. We appreciate it.

[The statement follows:]

STATEMENT OF ROBERTA BALSTAD MILLER

Mr. Chairman. I am pleased to have an opportunity to testify before the Subcommittee on Labor, Health and Human Services, and Education of the Senate Appropriations Committee. The Consortium of Social Science Associations (COSSA) represents over 175,000 social and behavioral scientists who are members of the 34 Member and Affiliate organizations in COSSA. A list of COSSA Members, Affiliates, and Contributors is attached to my testimony.

I wish to testify on the FY 1985 budget of the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (HHS). The administration has recommended a budget of $8 million for ASPE in FY 1985. This is down from $10 million in FY 1984 and from $14.7 million in FY 1984. From FY 1980 to FY 1985, this budget has declined by 67%, even without calculating the effects of inflation. Annual budgets for ASPE from FY 1980 to FY 1985 are given below:

Actual FY1980	Actual FY1981	Actual FY1982	Actual FY1983	Actual FY1984	Proposed FY1985
$24.0	$20.1	$13.4	$14.7	$10.0	$ 8.0

The proposed ASPE budget of $8 million in FY 1985 will permit the continuation of research projects for which funds have already been committed, but it will not permit ASPE to support any new research. Although the ASPE budget has been declining for some time, this most recent budget cut appears to have come out of recommendations reported by the President's Commission on Private Sector Initiatives (also known as the Grace Commission). The Grace Commission argued that research activities in HHS should be conducted in the various operating agencies of HHS and should not be undertaken within the office of the Assistant Secretary for Planning and Evaluation. In other words, the recommended decline of 20% in the ASPE budget appears to be part of a plan to phase out research activities in ASPE in favor of conducting research in HHS operating components, e.g., the Social Security Administration (SSA), the Health Care Financing Administration (HCFA), the Office of Human Development Services (OHDS), and the Public Health Service (PHS). These operating divisions all have well-defined, although relatively narrow, program responsibilities -- SSA for income security programs related to the elderly, HCFA for a variety of health and health insurance programs, PHS for analyses of mental and physical health problems, and OHDS for research on the handicapped, on young people with special problems, on the aged, and others.

Last year, the Consortium of Social Science Associations submitted testimony to this Subcommittee which described some of the research that has been supported by ASPE and argued that long-term research on issues of importance to HHS (issues such as understanding poverty and dependency or the problems of adequate resources for the aged) are much more sensibly located within ASPE than within operating agencies charged with particular programmatic responsibilities.

There are several reasons for this. First, and perhaps most important, the HHS operating agencies are mainly concerned with research designed to examine short-term issues in their specific areas of concern. Typically, the research activities undertaken by the operating divisions are concerned with immediate policy issues that come to the attention to the division rather than the department as a whole. For example, SSA would appropriately worry about the consequences of extending the retirement age for the financing of the social security programs, or of changing the criteria for disability; HCFA would be concerned about the consequences of various insurance plans; PHS with the treatment of schizophrenia or of mental disorders resulting from stress; and OHDS with programs designed to place handicapped people into normal settings rather than specialized institutional settings.

However, if all HHS research is focused on short-term issues, there will be little attention paid to long-term issues. Given the size and importance of the Department of Health and Human Services, a certain amount of its research program ought to be concentrated on emerging and potential problems and on understanding the nature and possible consequences of changes in the population, its health, and its welfare. The HHS operating units are not primarily research agencies. They have programs to administer and their first concern must be for those programs. The only place in HHS where such long-term research can be supported is in ASPE.

A second reason for maintaining an active research program in ASPE is its record -- ASPE has a long tradition of supporting basic and applied research that is not only highly germane to the policy issues of concern to HHS, but is also of good enough quality to stand the test of continued usefulness. This is in part because ASPE attracts highly professional scientific staff and in part because it has a broad mandate to deal with long-term policy problems. For example, ASPE has funded and continues to fund research projects in such areas as public and private pension systems and their impact on the economic status of the aged, family change and income change over time, and the study of wealth in the U.S. This latter study examines wealth in its broadest sense, looking at employer pensions and social security rights as well as income. The proposed reduction in the ASPE research budget from $10 million to $8 million may well put one or more of these research programs in jeopardy.

Finally, there are HHS policy alternatives that need to be researched that are quite unlikely to be undertaken by any of the operating divisions -- either because they lack explicit program responsibility or because the issues of concern cut across the jurisdictions of the operating divisions. For example, an alternative which involves elimination of a whole program or set of programs is unlikely to be seen as an desirable research topic by the operating division that has that program responsibility. The research projects mentioned above are also not likely to be funded in the operating divisions because they intersect the sphere of two or more divisions.

I do not know what motivated the Grace Commission to recommendation cutting the research budget in ASPE and transferring the research function to the operating agencies within HHS, but it is clear that they see research as something that ought to be managed at a level closest to the division with operating responsibility. This does not always make sense in the private sector, much less in the government. For example, it would be similar to a decision in General Motors that all research on automotive changes should be done within the Chevrolet or Pontiac Divisions. In this hypothetical view, corporate headquarters would have no responsibility for research beyond that which the operating divisions choose to do. Such an approach might make sense if GM's concerns were solely with next month's or next year's marketing problems. But if GM is at all concerned with the social and technological demands upon automobiles and automobile manufacturers in the future, or with what cars should look like or how they should be constructed in ten years, such an approach would be expensive and shortsighted. It does not make sense for operating divisions to duplicate or compete with each other in research nor to deal with related problems in unrelated research efforts.

I would urge the Senate Appropriations Subcommittee on Labor, HHS, and Education to recognize the importance of the research conducted by ASPE and the need for this research function by maintaining its budget at the FY 1984 level of $10 million and to suggest in report language that the Appropriations Committee sees the ASPE research function as an important component of HHS. The Department of Health and Human Services has massive responsibility for programs that affect all of American society. Without adequate support for long-term research activities designed to illuminate the policy issues that cut across the different parts of HHS, we will be less equipped as a nation to cope with the challenging problems of the next decade.

Members

American Anthropological Association
American Economic Association
American Historical Association
American Political Science Association
American Psychological Association
American Sociological Association
American Statistical Association
Association of American Geographers
Association of American Law Schools
Linguistic Society of America

Affiliates

American Association for Public Opinion Research
American Educational Research Association
Association for Asian Studies
Eastern Sociological Society
Economic History Association
Evaluation Network
Evaluation Research Society
History of Science Society
International Communication Association
International Studies Association
Law and Society Association
National Council on Family Relations
North Central Sociological Association
Northeastern Anthropological Association
Population Association of America
Regional Science Association
Rural Sociological Society
Social Science History Association
Society for American Archaeology
Society for the History of Technology
Society for Research in Child Development
Society for the Scientific Study of Religion
Society for Social Studies of Science
Southwestern Social Science Association

Contributors

University of California, Berkeley
University of California, Los Angeles
Center for Advanced Study in the Behavioral Sciences
Center for International Studies, Duke University
University of Colorado
Columbia University
Cornell Institute for Social and Economic Research
Cornell University
Georgia Institute of Technology
Harvard University
University of Illinois
Indiana University
Institute for Social Research, University of Michigan
University of Iowa
The Johns Hopkins University
University of Michigan
University of Missouri
University of Nebraska
New York University
University of Oregon
University of Pennsylvania
University of Pittsburgh
Princeton University
Social Science Research Council
University of Southern California
Stanford University
State University of New York at Stony Brook
Texas A & M University
Tulane University
University of Washington
University of Wisconsin, Milwaukee

STATEMENT OF RICHARD E. VODRA, PRESIDENT, COALITION FOR HEALTH FUNDING

Senator WEICKER. The next witness is Mr. Richard Vodra, president of the Coalition for Health Funding.

Mr. VODRA. Good morning, Mr. Chairman. I am Richard Vodra, president of the Coalition for Cystic Fibrosis.

We greatly appreciate the support the subcommittee has given us in the past to health programs and hope that it carries forward again this year.

Continued improvement in the health of the American people depends more on the continued strength of Public Health Service programs than on any other single factor. These programs, called discretionary in budget parlance but essential by everyone involved in the health field, are seriously short-changed in the President's budget.

Concern for health is part of our lives. We pray to have healthy children, we drink to each other's health, we hope to avoid chronic illnesses. For many centuries, these steps—hoping and praying—were all we could do. Only in this century have we begun to apply medical and public health knowledge to reduce the incidence of disease and promote the Nation's health.

Many of the changes we see today came about as a result of a systematic approach to the study of health and disease, led in this country by the National Institutes of Health and the National Institutes for Mental Health, Alcoholism, and Drug Abuse.

They came through improvements in the education of health professionals, assisted for the last 40 years by Federal programs. They came through specialized health programs designed to promote public health and help mothers and children, migrants, the mentally ill, and others in great need. They came through a national attack on communicable and infectious diseases and on unsafe or ineffective drugs.

Changes came, in short, through the programs of the Public Health Service that made it possible for better care to be delivered by health and mental health care professionals in hospitals, clinics, and offices across America and by public health professionals in community settings. The PHS, which now consumes only about 3 percent of each care dollar, is the agent of change.

It is the hope of the American people that this change, this progress, can continue. The opportunities abound:

A revolution in science, if continued, can find ways to cure or control the diseases that kill our children and cripple our parents, mentally and physically.

Improvements in prenatal care, if extended to all women in need, can further reduce the infant mortality rate.

New findings on preventing disease, if explained to the public and taught to providers, can keep us healthier and reduce health care costs.

Our knowledge of infectious disease control, if applied through public health practices and with the support of public health officers, can eliminate common diseases, control outbreaks, and make inroads into the prevention of chronic diseases.

The Coalition for Health Funding knows that this progress is possible, and that investment now is not discretionary if we truly care about our health and that of our children in the decade to come.

While we share the general concern about deficits, we know that the times have never been easy, and that the budget is always too large. Yet somehow those who had the responsibility in the past found the money that was needed to do the work that we benefit from today. We hope that this generation will in turn do its duty to help those whose futures depend on us.

The President's budget fails in this duty. If it were enacted, every part of the PHS would be able to buy less next year than it can now—less research, less infant care, less training, less control of disease, less everything.

The Coalition for Health Funding urges Congress to reject this philosophy and instead provide the funds needed to pursue our hopes and dreams and prayers for better health.

Thank you very much.

PREPARED STATEMENTS

The coalition would like to submit for the record an additional statement before your May 4 deadline outlining specifically our funding recommendation for PHS programs.

Senator WEICKER. The record will be open for inclusion of that statement, along with other statements submitted for the record on appropriations for the Department of Health and Human Services.

[The statements follow:]

STATEMENT OF RICHARD E. VODRA

The Coalition for Health Funding knows that this progress is possible, and that investment now is not "discretionary" if we truly care about our health and that of our children in the decade to come. While we share the general concern about deficits, we know that the times have never been easy, and that the budget is always too large. Yet somehow those who had the responsibility in the past found the money that was needed to do the work that we benefit from today. We hope that this generation will in turn do its duty to help those whose futures depend on us.

The President's budget fails in this duty. If it were enacted -- every part of the PHS would be able to buy less next year that it can now -- less research, less infant care, less training, less control of disease, less everything. The Coalition for Health Funding urges Congress to reject this philosophy and instead provide the funds needed to pursue our hopes and dreams -- and prayers -- for better health. Thank you.

The Coalition would like to submit, for the record, an additional statement outlining more specifically our funding recommendation for PHS programs.

Changes came, in short, through the programs of the Public Health Service that made it possible for better care to be delivered by health and mental health care professionals in hospitals, clinics, and offices across America and by public health professionals in community settings. The PHS, which now consumes only about 3 cents of each care dollar, is the agent of change.

It is the hope of the American people that this change, this progress, can continue. The opportunities abound:

- A revolution in science, if continued, can find ways to cure or control the diseases that kill our children and cripple our parents, mentally and physically;

- Improvements in prenatal care, if extended to all women in need, can further reduce the infant mortality rate;
- New findings on preventing disease, if explained to the public and taught to providers, can keep us healthier and reduce health care costs;
- Our knowledge of infectious disease control, if applied through public health practices and with the support of public health officers, can eliminate common diseases, control outbreaks, and make inroads into the prevention of chronic diseases.

THE IMPORTANCE OF THE PUBLIC HEALTH SFRVICE

Continued improvement in the health of the American people depends more on the continued strength of Public Health Service programs than on any other single factor. These programs -- called "discretionary" in budget parlance but "essential" by everyone involved in the health field -- are seriously shortchanged in the President's budget.

Concern for health is part of our lives. We pray to have healthy children, we drink to each other's health, we hope to avoid chronic illnesses. For many centuries, these steps -- hoping and praying -- were all we could do. Only in this century can we begin to apply medical and public health knowledge to reduce the incidence of disease and promote the Nation's health.

Many of the changes we see today came about as a result of a systematic approach to the study of health and disease, led in this country by the National Institutes of Health and the National Institutes for Mental Health, Alcoholism, and Drug Abuse. They came through improvements in the education of health professionals, assisted for the last 40 years by Federal programs. They came through specialized health programs designed to promote public health and help mothers and children, migrants, the mentally ill, and others in great need. They came through a national attack on communicable and infectious diseases and on unsafe or ineffective drugs.

STATEMENT OF STEVEN DEUTSCH, PH.D., CENTER FOR THE STUDY OF WORK, ECONOMY, AND COMMUNITY, UNIVERSITY OF OREGON, CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Thank you for the opportunity of appearing before you and presenting these remarks. My name is Steven Deutsch. I am Director of the Center for the Study of Work, Economy and Community and a Professor of Sociology at the University of Oregon. I am testifying on behalf of the Consortium of Social Science Associations, an organization that represents 175,000 social and behavioral scientists across the full range of the social and behavioral science disciplines. A list of COSSA Members, Affiliates, and Contributors is attached to my testimony.

I wish to urge that the Senate Appropriations Committee on Labor, HHS, and Education provide $22 million for research and evaluation in the appropriation of the Employment and Training Administration, Department of Labor. This is the amount requested by the administration for labor research last year. It was approved by this Subcommittee but not by the House and Senate conference committee, which reduced the ETA research budget for FY 1984 to $12.5 million. Our request of $22 million for FY 1985 is based both on the need for the Department of Labor to meet its congressionally imposed mandate to do research in this area. It is vital to have informed and applicable research for the making of intelligent and useful employment and training policies.

The history of governmental efforts in the field of labor market training and employment programs goes back more than two decades. The major legislation which pushed such involvement was the Manpower Development and Training Act (MDTA) of 1962. Twenty years ago I was one of many social science researchers in the country who worked with the Labor Department in attempting to speak to what James Conant of

Harvard then called "social dynamite." In Cleveland 77% of Black youth between ages 16 and 22 were then out of school and unemployed. The government correctly recognized the wastage of human resources and sought to play a temporary role of intervention in the lives of these young people to assist them in moving into productive roles in the economy. Job training and related evaluations of these intervention programs were seen as important components of governmental actions designed to assist in the transition to an automated economy in the 1960s.

A leading manpower economist in this period, Garth Mangum, wrote in his assessment of the period:

> The 1960s have been the most fruitful years in the history of efforts to improve the quality and increase the welfare of those who comprise the nation's manpower resources. The accomplishments have not been the objectives achieved, but the lessons learned and the experience base established for future programs. The final assessment of the period will depend upon the degree to which the lessons are applied in an integrated manpower program with appropriate balancing of services of federal, state, and local responsibility. (Garth Mangum, The Emergence of Manpower Policy, Holt, 1969:158)

The fact is that providing access to jobs, career skills, and a range of personal capabilities for disadvantaged youth, displaced workers and others whose roles in the economy were increasingly marginal in the 1960s were all extremely important. Critics have challenged the expenditure of governmental funds for such employment training programs and studies in light of the continued problems in the economy and the high rates of structural unemployment. However, economist Howard Wachtel correctly states the context for this appraisal when he asks, "But what would unemployment and income levels be if we had not spent so much money on employment training in the past 20 years?" (Howard Wachtel, Labor and the Economy, Academic Press, 1984:516)

One of the basic realities of the present era is the broad application of the so-called "new technology." Microprocessors and microelectronics, it is estimated, will have an impact in the next few years on at least one-half of the labor force. Instead of the limited consequences of so-called "Detroit automation" of the 1950s and 1960s, mostly focused upon basic production industries such as auto, steel, et al., which have experienced a decline in employment, the new technology will have profound consequences in the service sector and the industries which have experienced recent growth in employment. Thus, for the state of Oregon, the Employment Division projects a growth of 24,000 new jobs in electronics, but registers a loss of 25,000 jobs in the basic forest products industry between 1979 and 1982.

We are seeing some massive shifts in sectors, with consequent changes in job categories and requisite skills and training needs, and changes in work organizations and employment. What will these changes mean in terms of public and private sector policy-making and appropriate coordination between educational institutions and private industry? Between various levels of government and the labor market? Answers to these questions are imperative if we are to avoid a growth in the wastage of human resources, a rise in structural unemployment and a mis-match between the labor market needs and the educational and training activities in this country.

Informed policy demands a useful data base and appropriate research directed towards assisting the makers of policy. The Congress correctly has deemed the research function in the Employment and Training Administration (ETA) to be critical towards this end. The Job Training Partnership Act, passed in 1983, clearly states:

> To assist the nation in expanding work opportunities and assuring access to those opportunities to all who desire it, the Secretary shall establish a comprehensive program of employment and training research, utilizing the methods, techniques, and knowledge of the behavioral and social sciences and such other methods, techniques, and knowledge as will aid in the solution of the Nation's employment and training problems. The program required by this section may include, but need not be limited to, studies concerning the development or improvement of Federal, State, local, and privately supported employment and training programs; labor market processes and out-

> comes; policies and programs to reduce unemployment and the relationships thereof with price stability and other national goals; productivity of labor; improved means of forecasting and using forecasts of labor supply and demand at the national and subnational levels; methods of improving the wages and employment opportunities of low-skilled and disadvantaged workers; measuring and developing policies to eliminate worker shortages; and easing the transition from school to work, from transfer payment receipt to self-sufficiency, from one job to another, and from work to retirement.

Given this strong congressional mandate, it is most unfortunate that action was taken in the past year to delete and divert funds from the research activities in ETA. As a result, funds for data collection -- such as the very important National Longitudinal Surveys of Labor Force Participation -- and for research in employment training have been cut so severely that it is questionable that the ETA will be able to maintain any research program at all.

It is clear that the United States will continue to be in fierce global competition with other nations. Hence, pressures will increasingly be felt for increasing productivity, maintaining stable labor-management relations, improving our utilization of plants and equipment, and training a labor force which is equipped for the labor market needs of the future. Making correct policy decisions on these dimensions is critical -- and it requires adequate and appropriate research.

In the mid-1960s the country recognized the challenges of automation and the issues of technological change, unemployment and training. An Automation Commission was created and in 1965-1966 top level research was compiled to assist in the making of policies which affected education and training, employment and labor market programs, and the like. In the 1980's many industrial nations in the world have recognized the major challenges of the new technology and have assembled high level commissions to study the problem and make recommendations. These reports from Canada, France, Germany and elsewhere do not have a counterpart in the United States.

Congress should appropriate funds to the Employment and Training Administration with the clear expectation that research will be done in the next several years to provide information for future labor market and training policies.

Research supported earlier in the Manpower Administration and in the Employment, Evaluation and Research offices in the U.S. Department of Labor were critical for developing the governmental and public sector programs which we have seen over the past two decades. This was true for the decade of the 1960s with the Manpower Development and Training Act (1962), the 1970s with the Comprehensive Employment and Training Act (1973), and will be the case with the Job Training and Partnership Act (1983). The fact that the JTPA places more emphasis on private sector employment training and leaves coordination up to the states even more than was true with the CETA program in no way changes the need for focused research to indicate the appropriate and useful kinds of training, job placement, retraining and job skills acquisition, and linkages between governmental and private employers.

A few studies were completed last year which give us a clearer image of the shifts likely to occur in the American labor market at least through the remainder of this decade. Contrary to many notions about the high technology answer to the problems of our economic stagnation, these studies make it clear that growth will be in traditional occupational categories and that while there may be 92% growth in computer repairing jobs, that adds only 77,000 jobs nationally -- a fraction of the growth expected in auto repair jobs or a range of service sector employment. What is critically needed are studies which will inform us about the true effects of the massive investment in office automation which we are experiencing in the U.S. at the present. We also need research which will feedback to educational institutions and assist in their development to better prepare young people and first-time entrants into the changing world of work in the 1980s and 1990s.

The world's most automated engine plant was opened by Ford Motor Company in Cleveland in 1954. By the time I visited that factory for the first time in 1957 it was already outdated. That was a barometer about the rate of technological change in industry at that time. Today we are experiencing changes in the workplace and in the labor market that are far-reaching and amazingly rapid. For this nation to function successfully in the global economy of the future and best utilize the human resources in the society, we must plan for the future in terms of job training, in terms of employment opportunities, and in terms of productive and fulfilling work lives for our population.

Such planning and coordination between government and the private sector requires an informed set of policy makers. We need to have clear identification of the problems, evaluation of intervention programs, assessment of experimental programs in training and in the workplace, assessment of creative and cooperative labor-management relationships, and a good set of basic empirical data on what is transpiring today so that we may predict and plan for tomorrow.

A very modest investment in employment and training research can go a very long way towards helping this nation solve some of the problems of unemployment and the need for creative use of human resources to increase productivity, fulfillment at the workplace and the ability of our economy to function well.

There is a final point that must be underscored. For the past two decades a large number of American social researchers have been trained in the area of employment, labor force, work life research. Along with many others I entered a research and academic career at the beginning of the 1960s and gained from involvement in Department of Labor training and research projects. In turn, I have trained students in this area over the past decades and take pride in seeing their contributions; whether they are based in government, universities, industry or working with unions and other organizations. I am distressed that a doctoral student of mine at the present time holds the last dissertation award to be given in the employment and training area sponsored by the Department of Labor and the Social Science Research Council. Her work is directed towards policies which will assist in understanding the shifting role of women in the labor force and I am confident that her training will lead to useful contributions in the future.

That program has now been discontinued for lack of funds. Where will future researchers come from? I lament the demise of such few programs to support advanced training of researchers in the employment and training area. Again I would stress that an appropriation of $22 million in the Employment and Training Administration will help to revitalize this area and provide funds to train high quality researchers for the future.

The Consortium of Social Science Associations supports the legislative mandate of the Congress to conduct employment and training research. We urge that this Subcommittee provide $22 million for research in the Employment and Training Administration in FY 1985 and that the legislative report accompanying the appropriation repeat the research mandate adopted by Congress in the Job Training Partnership Act.

Statement of James G. Harris, Jr., Commissioner, Department of Human Resources, State of Connecticut

MR. CHAIRMAN, AND MEMBERS OF THE SUBCOMMITTEE, MY NAME IS JAMES G. HARRIS, JR. AND I AM COMMISSIONER OF THE DEPARTMENT OF HUMAN RESOURCES FOR THE STATE OF CONNECTICUT. I WOULD LIKE TO SPEAK TO YOU ON TWO ISSUES: MY SUPPORT OF THE

AUTHORIZATION TO EXTEND LOW INCOME ENERGY ASSISTANCE, THE COMMUNITY SERVICES BLOCK GRANT AND THE HEAD START PROGRAM FOR FIVE YEARS, AND MY OPPOSITION TO THE POTENTIAL MERGER OF THE SOCIAL SERVICES AND COMMUNITY SERVICES BLOCK GRANT. DUE TO TIME CONSTRAINTS, HOWEVER, I WILL LIMIT MY COMMENTS TO THE POTENTIAL MERGER OF THE BLOCK GRANTS. AS LONG AS IT CONTINUES TO REAR ITS UGLY HEAD I WILL CONTINUE TO SPEAK OUT AGAINST IT. IT IS IMPORTANT THAT THOSE ENTRUSTED WITH MAKING DECISIONS ON THE ISSUE FULLY UNDERSTAND THE FUNDAMENTAL DIFFERENCES BETWEEN THE TWO PROGRAMS AND THE RAMIFICATIONS OF SUCH A MERGER.

THE SOCIAL SERVICES BLOCK GRANT WAS DESIGNED TO SERVE THE VERY POOR, WELFARE CLIENTELE IN ORDER TO REDUCE DEPENDENCE ON PUBLIC ASSISTANCE AND INCREASE AUTONOMY. ITS MAJOR PROGRAM EFFORTS HAVE BEEN AIMED AT PROTECTIVE AND PREVENTIVE SERVICES FOR THOSE AT RISK OR FACING EMERGENCIES. SERVICES ARE PROVIDED THROUGH A CASE MANAGEMENT MODEL ON AN INDIVIDUAL BASIS TO CLIENTS.

IN THE STATE OF CONNECTICUT, A MAJOR INNOVATION IN THE PLANNING, PRIORITY SETTING AND FUNDING OF HUMAN SERVICE PROGRAMS HAS TAKEN PLACE. WE ARE NOW USING THE NEGOTIATED INVESTMENT STRATEGY, OR NIS PROCESS, IN ORDER TO ALLOCATE SOCIAL SERVICE BLOCK GRANT DOLLARS. THREE TEAMS, REPRESENTING THE STATE, MUNICIPAL AND NON-PROFIT SECTORS, HAVE DEFINED SERVICES, ARRANGED THEM BY PRIORITY, ALLOCATED DOLLARS TO EACH CATEGORY AND SET CRITERIA FOR SELECTING SERVICE PROVIDERS. A PERMANENT TRIPARTITE COMMITTEE REPRESENTING THE THREE NEGOTIATING SECTORS HAS BEEN ESTABLISHED TO OVERSEE THE IMPLEMENTATION.

THE AGREEMENT HAS DESIGNATED MY AGENCY, THE CONNECTICUT DEPARTMENT OF HUMAN RESOURCES, AS LEAD AGENCY FOR IMPLEMENTING THE BLOCK GRANT. THE HIGH PRIORITIES AGREED UPON REFLECT THE BASIC PHILOSOPHY OF THE SOCIAL SERVICE BLOCK GRANT: TO CARE FOR THOSE MOST VULNERABLE POPULATIONS IN THE STATE; THOSE AT GREATEST RISK. THEY INCLUDE ADOPTION, CHILD DAY CARE, CLIENT ORIENTED COORDINATION OF SERVICES, COMMUNITY BASED NON RESIDENTIAL CARE, DAY TREATMENT, EMERGENCY SHELTERS, AND SAFEGUARDING. A MULTITUDE OF STATE AGENCIES, TOWNS AND PRIVATE NON-PROFIT AGENCIES RECEIVE FUNDING THROUGH THIS BLOCK GRANT.

THE COMMUNITY SERVICES BLOCK GRANT, ON THE OTHER HAND, IS DIRECTED TOWARD COMMUNITY ACTION EFFORTS TO BREAK THE CYCLE OF POVERTY. IT OPERATES PROGRAMS THAT ATTACK THE CAUSES OF POVERTY IN NEIGHBORHOODS AND COMMUNITIES. ITS PROGRAMS WHICH ARE DEVELOPED WITH INPUT FROM THE POOR ARE GEARED AT ASSISTING THE POOR IN GAINING THE NECESSARY TOOLS FOR BECOMING ECONOMICALLY SELF SUFFICIENT.

THE MAJOR RECIPIENT OF FUNDS FROM THE COMMUNITY SERVICES BLOCK GRANT IS THE COMMUNITY ACTION AGENCIES. CAA'S IN MY STATE AND ACROSS THE NATION HAVE BEEN CHAMPIONS OF THE POOR SINCE THE EARLY SIXTIES. THE COMMUNITY ACTION AGENCY OF WHICH I WAS THE EXECUTIVE DIRECTOR HAS BEEN IN OPERATION OVER TWENTY YEARS. BECAUSE CAA'S OPERATE A COMPREHENSIVE RANGE OF PROGRAMMING AT THE LOCAL LEVEL, THEY ARE SUCCESSFUL AT MEETING IMMEDIATE NEEDS OF INDIVIDUALS AND FAMILIES WITHIN THEIR OWN NEIGHBORHOODS. AS A RESULT OF HAVING A STABLE BASE OF FUNDING THROUGH THE COMMUNITY SERVICES BLOCK GRANT, CAA'S ARE ABLE TO RUN PROGRAMS AIDING ALL AGES, FROM YOUNG CHILDREN THROUGH TO ELDERLY. THEY INCLUDE A MIX OF FEDERAL, STATE AND LOCAL EFFORTS SUCH AS HEAD START, NUTRITION, EMPLOYMENT, ENERGY ASSISTANCE, DRUG COUNSELING, NEIGHBORHOOD SERVICES, WEATHERIZATION AND SURPLUS COMMODITIES. IN CONNECTICUT, THE CAA'S TOOK ON BOTH THE EMERGENCY FOOD AND SHELTER AND THE SURPLUS COMMODITIES PROGRAMS LAST YEAR. ADMINISTRATIVE FUNDS FOR THESE PROGRAMS WERE MINIMAL TO CLOSE TO NON-EXISTENT. YET THEY WERE ABLE TO OPERATE THESE PROGRAMS, AND, IN THE CASE OF SURPLUS COMMODITIES, CREATE A PROGRAM THAT IS A MODEL TO THE NATION, THROUGH THE CONTINUED SUPPORT OF THE COMMUNITY SERVICES BLOCK GRANT. IN CONNECTICUT THIS YEAR, CAA'S HAVE LEVERAGED $67,000,000, ONLY 3.9 MILLION OF WHICH IS COMMUNITY SERVICES BLOCK GRANT FUNDS.

IN CONCLUSION, I BELIEVE THAT THE CRY TO COLLAPSE THE TWO BLOCK GRANTS IS ROOTED IN THE FOLLOWING HISTORICAL AMERICAN TRADITION ABOUT POVERTY. WHILE IT IS PERMISSIBLE TO RID POVERTY ON AN INDIVIDUAL BASIS, IT IS ALWAYS SUSPECT TO ASSIST THE POOR THROUGH SYSTEMATIC CHANGE. IT IS SUSPECT TO BREAK, IN AN ORGANIZED METHOD, THE CYCLES THAT ENTRAP PEOPLE IN STRUCTURAL POVERTY. SSBG IS SHADED TOWARD TRADITIONAL SERVICES OFFERED BY MAINSTREAM AGENCIES, WHILE CSBG

IS DIRECTED TOWARD COMMUNITY BASED ORGANIZATIONS FIGHTING TO CHANGE THE STATUS QUO.

EACH BLOCK GRANT SERVES A DIFFERENT PURPOSE AND A DIFFERENT CONSTITUENCY, AND EACH COMPLEMENTS THE OTHER'S EFFORTS. BOTH ARE VITAL TO MEET THE NEEDS OF LOW INCOME CITIZENS IN THIS NATION AND BOTH REQUIRE ADEQUATE, SEPARATE FUNDING IN ORDER TO ACCOMPLISH THIS TASK.

STATEMENT OF THE NATIONAL ASSOCIATION OF REGULATORY UTILITY COMMISSIONERS

I. Introduction

This statement is submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the Senate Committee on Appropriations on behalf of the National Association of Regulatory Utility Commissioners (commonly referred to as NARUC).

The NARUC is a quasi-governmental, nonprofit organization founded in 1889. Within our membership are the governmental agencies of the fifty States, the District of Columbia, Puerto Rico and the Virgin Islands which are engaged in the regulation of utilities and carriers. Our chief objective is to serve the consumer interest by seeking to improve the quality and effectiveness of government regulation in America.

II. Funding for LIHEAP

We appreciate this opportunity to express our strong support for continued funding of the Department of Health and Human Services' (HHS's) Low-Income Home Energy Assistance Program (LIHEAP), authorized by Section 2601 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35),in Fiscal Year (FY) 1985. The LIHEAP provides financial assistance to low income persons, including the elderly and the handicapped, for the payment of heating and cooling costs. The Executive Committee of the NARUC, which is the Association's policymaking body, overwhelmingly endorsed on February 26, 1981, the continuation of low-income energy assistance (NARUC Bulletin No. 15-1981, p. 22). Since that time the NARUC has actively participated in efforts to provide adequate funding for the program. Most recently, the Executive Committee adopted a resolution sponsored by the NARUC Ad Hoc Committee on Energy Conservation, during its Winter Meeting in Washington, D.C., on March 1, 1984, (NARUC Bulletin No. 12-1984, p. 26) urging Congress to increase the amounts of funds authorized and appropriated to the LIHEAP. In its resolution, the Executive Committee expressed the immediate importance of increased LIHEAP funding by noting that, "the severity of the current winter and the rising cost of both gas and electric heat will cause an increased need by low income persons for assistance . . . ."

As State commissioners who regulate retail electric and natural gas rates, our members are continuously aware of the burden that increasing fuel costs impose on the consumer. We are especially mindful of the hardships these increases work on the poor and elderly. Escalating energy prices afflict those least able to handle such increases: persons living on fixed incomes. In addition, these people face the problem of spiraling summer electric bills as they try to cool their households. Extreme heat can pose as serious a threat as extreme cold.

To further exacerbate the problem of rising gas and electricity costs, there has been an overall reduction in the Nation's public assistance benefits. The poor and elderly find themselves with less income assistance and higher utility bills. As a result, they become delinquent in their payments. Their delayed payments may mean that other utility ratepayers must carry the increased burden imposed on a utility's cost of service. This makes the problem of adequate energy assistance for low income households of concern to everyone.

In addition, delinquent payments often lead to disconnection by the utility companies of a customer's service. To provide some examples on the number of disconnects, derived from a combined analysis of four NARUC surveys, Manchester Gas Company of Manchester, New Hampshire, which serves the 18th most expensive service territory in the Nation, disconnected 1,206 residential customers in 1982 and Montana-Dakota Utilities of Bismarck, North Dakota, which serves the 20th least expensive service territory, disconnected 610 of its gas customers in North Dakota in 1982.[1] With respect to electricity, United Illuminating of Bridgeport, Connecticut, which serves the 13th most expensive service territory in the winter and the 22nd most expensive territory in the summer, disconnected 10,722 residential customers in 1982.[2] Appalachian Power of Charleston, West Virginia, which serves the 24th least expensive territory in the winter, disconnected 5,708 residential customers and Northern States Power Company of La Crosse, Wisconsin, which serves the 25th least expensive territory in the summer, disconnected 1,265 of its customers in 1982.[3] While there are various reasons why a residential customer does not pay his utility bill, for many low income citizens it is simply that they were forced to make a choice for their family between "heating or eating."

Funding for the LIHEAP has consistently fallen short of the program's needs. In FY 1983, the administration sought only $1.3 billion for this program. The Congress found that request inadequate and appropriated $1.975 billion. Then for FY 1984 the Administration, disregarding the continual increase in energy prices and rising inflation, again requested $1.3 billion. The Congress appropriated $1.875 billion. Although lower income households are finding that the burden of providing their homes with heating and cooling has not diminished since 1983, they are expected to try to carry this burden with less energy assistance in 1984 than they had the previous year. Many States have already exhausted their portion of the $1.875 billion that was appropriated for FY 1984. Recently, Congress approved H.J. Res. 493, which will provide an additional $200 million to the LIHEAP to try to help ease this problem of initially insufficient program funding.

---

[1] NARUC Survey of Residential Gas Bills, Winter 1982-83, May 16, 1983; NARUC Survey of Electric and Natural Gas Utility Uncollectible Accounts and Service Disconnections for 1982, August 31, 1983.

[2] NARUC Survey of Residential Electric Bills, Winter 1982-83, May 31, 1983; NARUC Survey of Residential Electric Bills, Summer 1983, January 3, 1984; NARUC Survey of Electric and Natural Gas Utility Uncollectible Accounts and Service Disconnections for 1982, August 31, 1983.

[3] Id.

The need for increased assistance to low income persons under this program remains a vital concern of the NARUC. However, the Administration's budget request for FY 1985 is $1.875 billion, which has already proven to be inadequate. By the time this amount is divided between all fifty States, the District of Columbia, Puerto Rico, the American Virgin Islands, Guam, American Samoa, the Northern Marianas, the Trust Territories of the Pacific and more than 100 Indian tribal organizations, there is very little money to go around.

III. Energy Conservation

A State is usually compelled to direct all of its LIHEAP funding towards the immediate problem of needed financial assistance to the low income and elderly to relieve the burden of energy costs, although a State is presently allowed to use 15% of its share of funds for weatherization assistance. The NARUC believes that continued emphasis on energy conservation programs such as the Weatherization Assistance Program, administered by the Department of Energy's Conservation Grants Program, provides a long term answer to the problem of high home energy costs. Such programs address the root of the problem by providing the State and local governments with Federal funds to be used for the provision of labor and materials required to make the dwellings of low income persons energy efficient (i.e., insulating). The end benefit of these weatherization measures is lower utility bills. Unfortunately, by the time a State has rendered financial assistance to those households eligible under LIHEAP, there is seldom money left for weatherization measures.

To help promote a better understanding of the importance of effective energy conservation measures, the Ad Hoc Committee on Energy Conservation is presently conducting a comprehensive study of the Nation's energy conservation experience over the last decade. The study will collect, evaluate and analyze the results of energy conservation efforts made by Federal agencies, State commissions, utilities and consumers.

IV. Conclusion

Since its inception, the LIHEAP has enjoyed strong bipartisan support in Congress as well as support from State and local governments and private organizations. The members of the NARUC respectfully urge you to ensure that next winter will be a better one for this Nation's elderly and poor by appropriating at the minimum $2.5 billion for LIHEAP funding.

LETTER FROM DEPARTMENT OF HEALTH AND HUMAN SERVICES, REGIONAL OPERATIONS FOR FACILITIES ENGINEERING AND CONSTRUCTION, REGION VIII

April 16, 1984

Department of Health and Human Services
Regional Operations for Facilities
Engineering and Construction, Region VIII
1961 Stout Street, Room 1152
Denver, Colorado 80294

APR 23 AM 9 45

The Honorable Lowell A. Weicker
Chairman, Subcommittee on
Labor, Health and Human Services,
and Education Appropriations
United States Senate
Washington, D. C. 20510

Dear Mr. Chairman:

A proven efficient organization of engineers, architects, and supporting personnel, DHHS/ROFEC, that has over the years served our nation well in times of stress and peace, is being destroyed without its staff having been consulted or given the opportunity to refute the recommendations arrived at by the Grace Commission whose members lacked the technical expertise in the fields of knowledge that govern our responsibilities.

The ROFEC staff, Region VIII, which continually receives recognition and commendations from applicants, various governmental authorities and fellow peers, represents the technical excellence existing in all the ten Regions approximating centuries of professional experience that is now scheduled for abolition by not later than September 1984 under the recommendations of the Grace Report. We strongly assert that the economic conclusions and recommendations in the Report as applicable to ROFEC are not valid, and are refuted by facts which were not taken into consideration. We emphatically state that the proposed reassignments of ROFEC functions can only result in increased costs, disruption of services, and loss of exceptional technical services. The abolition of ROFEC, as planned in the Report, is a return to the proven limited effectiveness and costly operations of the past.

In 1970, FECA/ROFEC was created to provide more cost effective architectural/engineering services for all agencies in lieu of each agency within DHEW having its own staff. The enclosure, Focus on FECA, 1970, identifies that the purpose of the formation of FECA and the ROFECs was to streamline the functions of government and increase the efficiency of architectural/engineering services. The proposed reorganization would reverse this concept and make each agency again responsible for their own architectural/engineering services. [redacted] We recommend that the concept of a pooled resource is the most effective way to contain costs and provide the Department with the best possible architectural/engineering services.

Our prescribed duties are assigned to us based upon Congressional Regulations and Federal Executive Orders governing Direct Federal and Federally Assisted Construction during the design, bidding and construction phases of approved projects. We are a procurement and technical service organization to Public Health Service, Indian Health Service, U. S. Department of Agriculture FMHA on rural health hospitals and clinics, U. S. Department of Education on elementary, secondary, higher academic facilities and college housing, Small Business Administration, Indian Preference Act, Federal Emergency Management Administration, U. S. Department of Labor Office of Federal Contract Compliance Programs, Office for Civil Rights for compliance with Section 504 of P.L. 93-112 and P.L. 90-480 Physically Handicapped Accessibility Standards, provide engineering surveys and planning for the Social Security Administration, and are Fire Safety Consultants to Health Care Financing Administration. Our technical expertise is required in the disposal and recovery of land and buildings (often running into millions of dollars per transaction) under the Surplus Real Property Program. This same expertise is required for recovery under the Hill-Burton Act (grants, loans and loan guarantees for construction and modernization of hospitals and other medical facilities) generally involving millions of dollars. We review budgets, proposals of scope of construction, prepare and review contracts, change orders, and make inspections.

It is our technical agency that applies its deeply dedicated concern, analysis, knowledge and abilities to the broad spectrum that includes the environment of the school child with developmental disabilities attributable to mental retardation and other neurological conditions that vitally impact the design of Preschool Day Care Facilities, to the environment of the physically handicapped and the elderly. When "sputnik" spurred the Governments' financial support for the development of higher academic science facilities, we were in the forefront evaluating the planning and construction of the facilities even as today we are involved in the application of solar design.

In addition to our regular duties, we are tasked to perform disaster surveys during periods of National Emergencies such as tornadoes, hurricanes, floods and earthquakes on and off the Continental United States. We inform, coordinate, and advise State and local authorities in the fulfillment of our responsibilities and have achieved an excellent rapport.

In terms of professional excellence, energy conservation, economic advantage, and efficient operations and maintenance, we have produced safer, more economical functional structures than would have occurred if we had not existed. Our concern for functional facilities that meet all mandatory requirements and the applicants' needs has resulted in savings of millions of dollars in construction and maintenance costs and projects completely integrated in functions and operations. Our technical reviews have contributed to more economical budgets and life cycle costs, and show the pressing need for continued competent overviews by professional ROFEC architect/engineers. None of the above functions are duplicated by other government agencies. Most applicants seek ROFEC's professional help because of their lack of expertise and experience with Federally Assisted Programs.

We request that Congress hold hearings to ensure that the Executive Branch carries out its responsibilities so that the health and safety and needs of the public and the best interests of the elderly and disabled are fully protected, and that the abilities of the government to respond in times of emergency are not impaired. As responsible civil servants, we stand ready to testify in these areas as to the needs and the justification of a ROFEC.

We respectfully urge your support for the continuation, intact, of ROFEC/DHHS to which we have given our loyalties, contributed our knowledge, abilities, and years of service.

We request that this letter be made part of the record of any hearings held by the Congress in regard to these matters.

Sincerely,

The ROFEC staff, Region VIII

Raymond B. Eakle	Raymond Eakle
Patricia C. Gibson	Patricia C. Gibson
Robert I. Haught	Robert I Haught
Elwyn Holtrop	Elwyn J Holtrop
Ralph E. Kelley	Ralph E Kelley
Kenneth E. Kellogg	Ken Kellogg
E. W. McIntire	
Jerry D. McKinney	Jerry D. McKinney
Robert P. Merritt	Robert P Merritt
Vern Monroe	Vern Monroe
Sharon B. Moore	Sharon B Moore
Robert D. Pearson	Robert D Pearson
Granville K. Peterson	Granvill Peterson
Saundra M. Plamondon	Saundra M Plamondon
Ada Segal	Ada Segal R.A.
Richard Snapp	Richard Snapp Facilities Engr.
Lucile V. Strauch	Lucile V. Strauch
Barbara J. Tamburelli	Barbara J. Tamburelli
Kurt E. A. Vragel	Kurt E A Vragel P.E. Mech. Engr.
Jerome D. Weller	Jerome D Weller P.E.

NEW HEW FACILITIES ENGINEERING AGENCY

The Facilities Engineering and Construction Agency (FECA) was established April 5, 1970, after completion of a Task Force assignment to plan such an agency, made by Secretary Finch September 3, 1969. Gerrit D. Fremouw, who was named Director of FECA, is an engineering consultant who served 26 years in the U. S. Armed Forces, including 15 years in Headquarters, Strategic Air Command, during which he was Deputy Chief of Staff, Civil Engineering, for five and one-half years. In this position he was responsible for the planning, design, construction, and operations and maintenance of facilities worth over $5 billion at world-wide SAC aircraft and missile bases. Mr. Fremouw will be assisted by Walter E. Mylecraine, formerly Assistant Commissioner for

Construction Service, Office of Education; and Edgar G. Huddleston, Jr., formerly Director of the Division of Property Management, Office of General Services, HEW.

Mission of FECA

FECA consolidates architectural/engineering guidance and support for all Department construction programs (both Federally assisted and direct Federal); such services were formerly furnished by the Office of Construction Service in the Office of Education and by several construction support agencies for the health programs.

The agency's overall goals are (1) to improve services to the grantee community; (2) to effect savings in construction costs through the application of such techniques as value engineering and improved design and space utilization; and (3) to implement a facilities management system for DHEW real property.

Background

There are presently 21 Federally assisted construction programs and 10 direct Federal special-purpose construction programs in the Department of Health, Education, and Welfare. These programs expend annually about a billion dollars, which generates a total construction expenditure of about $4 billion. It had been recognized for some time that a central contact point for architectural/engineering services needed to be established for applicants and that design and construction procedures and review functions needed standardization. These changes simplify requirements for applicants and also make for more efficient operations. An added bonus from the consolidation is the uniting of architectural/engineering capability so that specialties can be intermingled as needed in the education and health areas; and certain expertise not presently available in either area has been added, including professional electrical and mechanical skills.

The study of DHEW-occupied property (both owned and leased) pinpointed the lack of an overall integrated facilities management system at the Department level which would maintain a cognizance of all property and therefore serve for both short- and long-range planning. Included in the system, now incorporated under FECA, are continuing inventory, condition-coding, design, construction, and operations and maintenance.

Organization

FECA has four operating offices and four staff offices (see organization chart on page 2). The Office of Federally Assisted Construction, as indicated by its title, is concerned with construction under the HEW grant and loan programs. The Office of Facilities Engineering Management and the Office of Facilities Operations and Maintenance are concerned with the construction of direct Federal projects and with the management of all HEW real property. The Office of Architectural and Engineering Services is responsible for selecting methods and means for providing architectural/engineering design and related construction services for Federal special-purpose buildings and for developing standards, criteria, and guides for both direct Federal and Federally assisted construction.

Research and Development Program

Developments in building technology, such as systems building, make it of paramount importance to institute a facilities Research and Development program which will keep abreast of these innovations and encourage their use, both in advisory services to applicants and in the construction of DHEW-owned property. It is the aim of FECA's R and D program to apply "state-of-the-art" research and to foster advanced R and D. Also included under the auspices of this program will be career development courses for professional personnel.

Regional Offices

Under each DHEW Regional Director there is an Office of Facilities Engineering and Construction which consolidates the regional architectural/engineering personnel of the health and education programs. This Office, headed by a Regional Engineer, is under the technical guidance of FECA and administers all delegated responsibilities, which include continued support to Federally assisted programs, architectural/engineering services for Federal projects as directed, consultant services to Department physical plant supervisors, and inspection of physical plant for safety and health standards. (See list of Regional Engineers on page 4.) The Metropolitan Engineering Staff is the counterpart of a Regional Office for direct Federal construction in the Washington-Baltimore area.

Priorities Among FECA's Objectives

(1) To stimulate leadership to grantee community to insure a national approach to health, education, and welfare facilities.
(2) To spearhead efforts to lower facility costs by R & D innovative building systems utilization and efficiently applied consulting professional architectural/engineering services to applicants' architects/engineers.
(3) To place special emphasis on value engineering and life-cycle cost analysis.
(4) To create integrated agency and Department long-range facility plans utilizing facility boards.
(5) To develop long-range occupancy plans for DHEW in large metropolitan areas.
(6) To institute a deep-look program (complete analysis) for HEW real property, including condition-coding.

STATEMENT OF DR. MORTON CORN, PRESIDENT, ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY, DIRECTOR, EDUCATIONAL RESOURCE CENTER FOR OCCUPATIONAL HEALTH AND SAFETY, SCHOOL OF HYGIENE AND PUBLIC HEALTH, JOHNS HOPKINS UNIVERSITY

Senator WEICKER. Thank you very much.

Next, we have Dr. Morton Corn, president of the Educational Resource Center for Occupational Health and Safety of Johns Hopkins University.

Dr. CORN. Thank you, Mr. Chairman. I thank you for this opportunity to appear on behalf of 15 educational resource centers who have been peer reviewed and qualified to perform educational training for occupational physicians, health nurses, and industrial hygiene in this industry.

In the interest of time, I will paraphrase my statement.

The educational resource centers were created in 1976 to act as centers for such education and training in recognition of the shortfall in technical competence to implement the Technical Safety and Health Act.

In my first experience in 1976, I was serving as Assistant Secretary for Occupational Safety and Health and was called by those drafting the bill for input as an educator, not in my official capacity.

Contrary to the statements recently voiced, the program was not conceived as a pilot program. It was recognized by those drafting it that it, indeed, required long-term support and nurturing to help the universities get these programs on board.

All these schools are currently seeking diversification of funding and are making progress, but the administration for 3 years, as you know, has not included any funding for this support in its budget.

Assistance to students by use of stipends was also recognized as a necessity, and the recent national economy has imposed hardships on universities. So it is simply making it impossible for these programs to survive if Federal funding was curtailed.

Indeed, the planning under current national conditions has been extremely difficult for these universities. I would like to refer you to exhibit 1, in the back, which plots the number of graduates from the program since 1976 and the funding.

We have learned that there is about a 2-year, possibly a 3-year lag in these funds. We are now experiencing the results of the reduction of funding from a peak of $12.9 million in 1980 to $5.8 million in each of the last 2 years.

With a decrease in the number of graduates, the universities hire, they recruit students, and the outputs are 2 to 3 years down the road. I have indicated the ERC estimates for 1985 with zero-based funding. I collected these figures by contacting each director in February and March.

As an indication of what has been happening, I quote certain statements in those questionnaires from the directors: Faculty positions not filled; capacity for students halved; lost attending physician faculty member; all ERC faculty took salary reductions; one faculty member, safety sciences, terminated; cancellation of two safety courses; two industrial hygiene positions eliminated.

And I could go on. The ERC's are hanging on, but at a reduced level of effectiveness. Full funding as originally conceived is needed to effectively implement this program.

We estimate that if there is no Federal funding this year 25 percent of the numbers of graduates from 1981 will be graduated in 2 years down the road.

Furthermore, the programs would not contain the multidisciplinary focuses of the ERC's. The ones that would survive would perhaps be a medical program at one university, safety at another, and to get this job done these disciplines must interact with each other.

We heard Matilda Babbitz earlier speak about how nurses are not recognized. I don't think that would happen if people were getting their training at ERC's, where physicians, nurses, and engineers live together.

In retrospect, I think that the 1976 decision by the Congress was perhaps our finest hour. Their training program has been one of the best that we have ever had.

This is cost effective education. We estimate $7,000 for each graduate, $70 for each attendee in a continuing education course. The National Safety Council estimates $32 billion a year as a result of over 2 million injuries and fatalities in the workplace. A well-trained professional, with only a few contributions, would have a major impact on those $32 billion, and I think, right off, this investment in education quite rapidly.

We conclude that these programs are struggling to achieve permanency. Many have already disappeared with faculty teaching in other more traditional fields or leaving the university, and we believe that this program has proven its effectiveness and urge you to consider funding at the initially conceived $1 million for ERC, and call your attention to the last enclosure, in that there are project training grants at individual schools in one area of potential competence, and we recommend that that training should be funded at $1.5 million, or $16.5 million for NIOSH training programs in the budget.

And I would be pleased to answer any questions that you may have.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Doctor. I appreciate your statement.

[The statement follows:]

STATEMENT OF DR. MORTON CORN

I appreciate the opportunity to speak to this committee on behalf of academic programs in occupational health and safety. Drs. Raymond Suskind and Don B. Chaffin met with this committee during the preceding two years for the same reason that I am here today, namely to clarify the critical need for professional education in occupational health and safety. The past year's presentations demonstrated how federal training funds, made available for such purposes through the National Institute for Occupational Safety and Health during the late 1970's provided the means to initiate academic programs in occupational health and safety at various universities. In recognition of the acute need for such program funding, Congress in 1976 authorized an expansion of the existing training programs to include the creation of 20 multidisciplinary Education Resource Center (ERC's). During the subsequent four years (1977-80) funding was expanded for this purpose from $2.9 million to $12.9 million, which allowed 12 of the intended 20 Centers to be funded by 1980. During this period appropriate faculty were recruited, new curriculii which stressed the multidisciplinary nature of occupational safety and health were established, and a concerted effort to attract outstanding undergraduate science and health students to the field was initiated at the universities. This resulted in the existence of over 100 different academic degree programs by 1980, offering degrees related to occupational medicine, industrial hygiene, occupational health nursing, and occupational safety. These programs primarily resided in the 12 new Educational Resource Centers, with assistance of the single discipline training projects available in 29 other universities at the time. At the present time there are 15 NIOSH supported Educational Resource Centers.

In 1976 I was serving as Assistant Secretary of Labor for Occupational Safety and Health and provided input to those drafting the omnibus bill that resulted in ERC's being funded by the Federal Government. Contrary to statements I have heard recently, the program was not conceived as a limited, five year program. It was recognized that schools must be financially assisted to offer quality programs in occupational sfaety and health and that self-supporting programs would require many years for development. Assistance to students by means of tuition and stipends was also recognized as a necessity. Hardships imposed on universities by national economic conditions during the 1980's have placed even greater stress on the need for continued Federal funding in this area so vital to employee health and productivity.

The real possibility of curtailment of ERC funding each year in recent years has made program planning at ERC's uncertain to say the least. Under such conditions of uncertainty, retention of faculty and recruitment of students is difficult.

The number of professionals graduating from these programs increased in approximate proportion to the funding increase, from 217 to 747 in 1980. [See Exhibit 1]

The development of the 12 Educational Resource Centers in the late 70's also provided much larger continuing education opportunities for those already practicing in the field. In 1977 approximately 1,600 professionals attended courses at the various universities and within NIOSH. In 1980 this number increased to almost 10,000 attendees. [See Exhibit 2]

Despite the success of the academic programs to increase the number of well trained professionals in the field during the late 70's, the federal funding was drastically reduced in subsequent years, from a high of 12.9 million dollars in 1980 to the current 5.8 million dollars appropriated in the FY84 budget. The number of graduate degrees is declining. The drastically reduced budget of 5.8 million dollars in NIOSH support this year and last year has meant that only about 50 academic degree programs are now supported within the various universities, compared to over 100 in 1980. The locations of these programs are indicated on the attached map.

I surveyed the ERC's during February and March of this year to ascertain the impacts of the reduced funding of the past two years. Random selection of questionnaire replies illustrates the severe program impacts of less than full funding.

> "staff reductions; increased reliance on lectures for teaching."
>
> "faculty position not filled."
>
> "curtailed number of seminars; curtailed outreach activities."
>
> "capacity for students halved."
>
> "lost attending physician faculty member."
>
> "all ERC faculty took salary reductions."
>
> "One faculty member (safety sciences) terminated; cancellation of two safety courses."

"Two industrial hygiene positions eliminated."

"Two occupational medicine faculty positions eliminated."

I could continue with citation of problems with equipment inadequacies, decreased numbers of courses and seminars offered, and reduced numbers of students. The conclusion is inescapable. The ERC's are "hanging on" but at a reduced level of effectiveness. Full funding, as originally conceived, is needed to effectively implement this program. All are experiencing demands by potential students which cannot be effectively met.

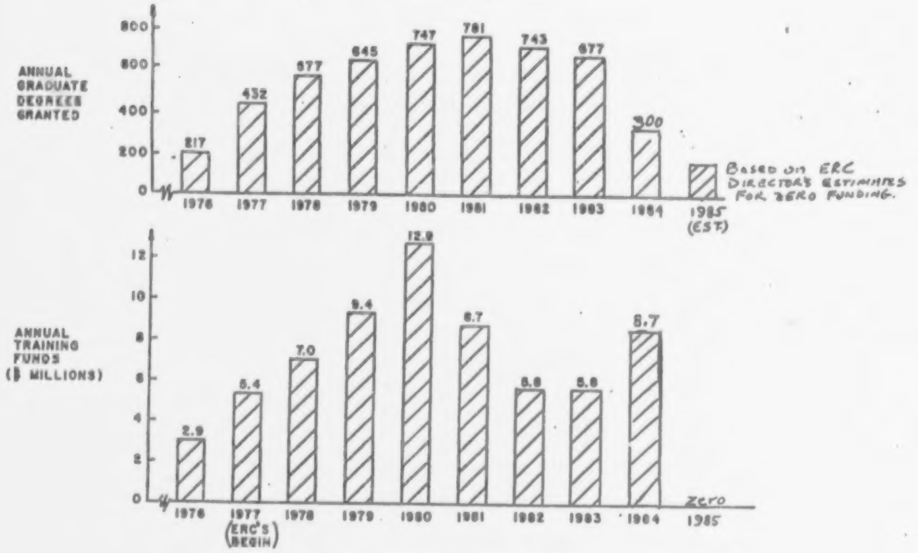
If no federal funding is provided in 1985, the number of graduates completing their programs will further drop to approximately 25% of the number graduated in 1981, and only about 20 graduate degree granting programs could be expected to remain viable in the Country for years to come. Further, the programs that would remain probably would revert to single discipline training utilizing faculty with existing but narrow expertise. These survivor programs would also have little capacity to meet the rapidly expanding demand for continuing education of professionals already in the field, with only one-third of the present courses expected to be available to such persons in 1985.

In retrospect, the decision by Congress in 1976 to expand the support of occupational health and safety training was wise. The universities responded rapidly to this challenge, and initiated a large number of new programs to meet the country's needs. Those same needs exist today as in 1977. The number of new professionals needed in 1981 was estimated by NIOSH to be seven times greater than the total output of the programs funded in 1981. Though the present manpower demand has weakened since 1981, the demand for well trained professionals still exceeds the supply, and with an upturn in our economy, the demand will increase further. Who will train these professionals with so many of the current programs failing due to the funding reductions? And what will be the quality of that training? Furthermore, the federal cost of such education is low (approximately $7,000 for each degree graduate and $70 for each attendee in a continuing education course). Consider that the total cost of occupational injuries and illnesses is conservatively estimated by the National Safety Council at over 32 billion dollars a year as a result of over two million injuries and fatalities in the workplace. If a well-trained professional can prevent only a few injuries or illnesses he or she has easily paid for their education.

It should be clear from the preceding that the new academic programs established in the late 1970's did not have time to achieve permanency in their home institutions. Many have already disappeared with faculty teaching in other more traditional fields, or going into private industry. The contracted economy of the last couple years has also meant that state agencies and private industry have not been able to increase support for such training over that provided in 1980.

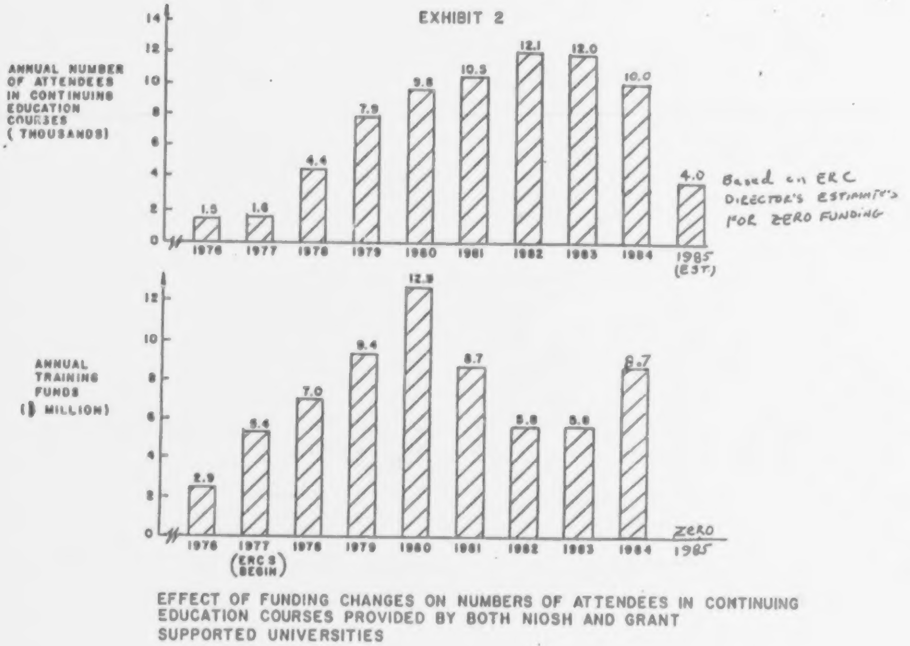
Recall that the intent of the Congressional Appropriation for the ERC programs in 1976 was to have within five years 20 Centers, each funded at approximately one million dollars annually. NIOSH's peer review process has established that 15 universities now meet minimum criteria to be Educational Resource Centers. If the originally intended funding of one-million dollars each for these 15 Centers could be provided, the academic base necessary to better meet our Country's manpower needs and establish viable Centers within each university in future years would be achieved. It must also be recognized that the single discipline training projects in other universities are vital, as they often produce special expertise needed in the field. These have been equally impacted by the training fund reductions over the last few years. Funding for these single discipline training project grants should be increased to approximately 1.5 million dollars. In summary, we strongly urge you to consider restoring funding at a level of 16.5 million dollars for the NIOSH training programs in the FY85 budget.

EXHIBIT 1

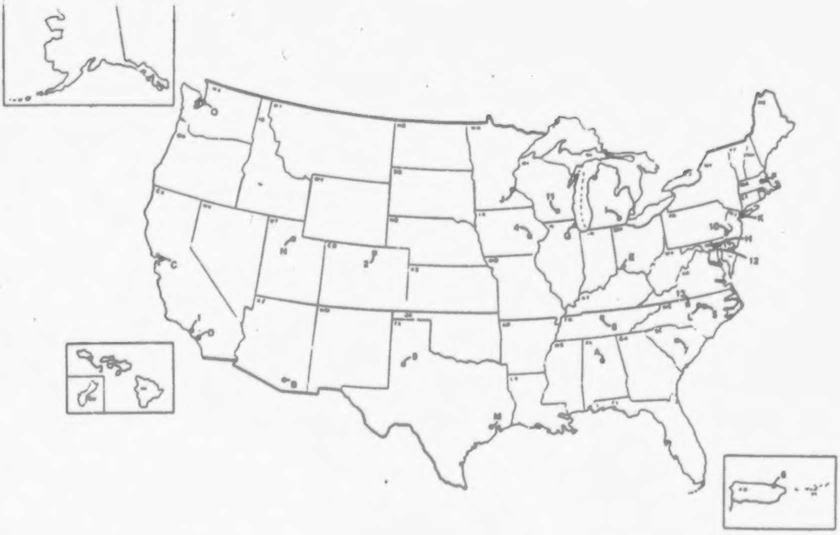


EFFECT OF FUNDING CHANGES ON NUMBER OF GRADUATES FROM BOTH ERC AND SINGLE DISCIPLINE PROJECT GRANTS

EXHIBIT 2



EFFECT OF FUNDING CHANGES ON NUMBERS OF ATTENDEES IN CONTINUING EDUCATION COURSES PROVIDED BY BOTH NIOSH AND GRANT SUPPORTED UNIVERSITIES



EDUCATIONAL RESOURCE CENTERS

A — ALABAMA EDUCATIONAL RESOURCE CENTER
University of Alabama in Birmingham
School of Public Health
Medical Center, University Station
Birmingham, AL 35294
(205) 934-7032
Vernon E. Rose, Dr. P.H., Director

B — ARIZONA EDUCATIONAL RESOURCE CENTER
University of Arizona
Arizona Health Sciences Center
1145 North Warren — ACOEH
Tucson, AZ 85724
(602) 626-6835
Herbert K. Abrams, M.D., Director

C — CALIFORNIA EDUCATIONAL RESOURCE CENTER — NORTHERN
University of California, Berkeley
306 Earl Warren Hall
Berkeley, CA 94720
(415) 642-0761
Robert C. Spear, Ph.D., Director

D — CALIFORNIA EDUCATIONAL RESOURCE CENTER — SOUTHERN
University of California, Irvine
Department of Community and Environmental Medicine
Irvine, CA 92717
(714) 752-2338
D. Dwight Culver, M.D., Director

E — CINCINNATI EDUCATIONAL RESOURCE CENTER
University of Cincinnati
Institute of Environmental Health
3223 Eden Avenue
Cincinnati, OH 45267
(513) 872-5701
Raymond R. Suskind, M.D., Director

F — HARVARD EDUCATIONAL RESOURCE CENTER
Department of Environmental Health Sciences
Harvard School of Public Health
665 Huntington Avenue
Boston, MA 02115
(617) 732-1260
Richard R. Monson, M.D., Director

G — ILLINOIS EDUCATIONAL RESOURCE CENTER
University of Illinois
School of Public Health
P.O. Box 6998
Chicago, IL 60680
(312) 996-7887
Bertram W. Carnow, M.D., Director

H — JOHNS HOPKINS EDUCATIONAL RESOURCE CENTER
Johns Hopkins University
School of Hygiene and Public Health
615 North Wolfe Street
Baltimore, MD 21205
(301) 955-3602
Morton Corn, M.D., Director

I — MICHIGAN EDUCATIONAL RESOURCE CENTER
University of Michigan
Department of Industrial and Operations Engineering
1260 G.G. Brown Laboratory
Ann Arbor, MI 48109
(313) 763-2248
(FTS 8-363-2248)
Don B. Chaffin, Ph.D., Director

J — MINNESOTA EDUCATIONAL RESOURCE CENTER
University of Minnesota
School of Public Health
1162 Mayo Memorial
420 Delaware Street, S.E.
Minneapolis, MN 55455
(612) 221-6770
Robert O. Mulhausen, M.D., Director

K — NEW YORK/NEW JERSEY EDUCATIONAL RESOURCE CENTER
Mt. Sinai School of Medicine
1 Gustave Levy Place
New York, NY 10029
(212) 650-6173
Irving J. Selikoff, M.D., Director

L — NORTH CAROLINA EDUCATIONAL RESOURCE CENTER
109 Conner Dr.
Professional Village
348 A. Suite 1101
Chapel Hill, NC 27514
(919) 962-2101
David S. Fraser, Sc.D., Director

M — TEXAS EDUCATIONAL RESOURCE CENTER
The University of Texas Health Science
Center at Houston
School of Public Health
P.O. Box 20186
Houston, TX 77025
(713) 792-7456
Edward Fairchild, Ph.D., Director

N — UTAH EDUCATIONAL RESOURCE CENTER
Rocky Mountain Center for Occupational and Environmental Health
University of Utah Medical Center
DFCM Room BC 106
Salt Lake City, UT 84132
(801) 581-8719
William N. Rom, M.D., Director

O — WASHINGTON EDUCATIONAL RESOURCE CENTER
University of Washington
Department of Environmental Health SC-34
Seattle, WA 98195
(206) 543-1060
John T. Wilson, Jr., M.D., Director

PROJECT TRAINING GRANTS

	City		City
1. California State — Northridge	L.A.	7. Univ. of South Carolina	Columbia
2. Colorado State Univ.	Ft. Collins	8. Meharry Medical College	Nashville, Tenn.
3. Univ. of Hawaii	OAHU	9. Texas Tech. University	Lubbock, Texas
4. Univ. of Iowa	Iowa City	10. Temple University	Philadelphia
5. St. Augustine College	Raleigh, N.C.	11. University of Wisconsin	Madison
6. Univ. of Puerto Rico	San Juan	12. Catonsville Community College	Baltimore
		13. North Carolina A&T	Greensboro, N.C.

STATEMENT OF LARRY C. DEEB, M.D., CHILDREN'S CLINIC, FLORIDA DEPARTMENT OF HEALTH AND REHABILITATION

Senator WEICKER. Next we have Dr. Larry Deeb of Children's Clinic of Florida.

Dr. DEEB. Thank you, Senator. I am here on behalf of the Diabetes Control Program at the national disease control and wish to speak to the funding of that—funding of CDC.

I am a practicing physician and member of the advisory council for the government in Florida.

CDC is the public health arm of the Federal Government and has a history of cooperation with the State and local health departments and also is the arm of the Federal Government which practitioners look to as an authority. CDC has a past history of cooperation with the State and local health departments and with physicians in the community.

CDC also has a history of consensus building among physicians and has done this also for diabetes. CDC and the Diabetes Control Program have allowed experts to develop and evolve a program that I think is worthy of your consideration and further funding.

CDC and the Diabetes Control Program have looked at diabetes from the epidemiological point of view and have looked at what's preventable in diabetes. They have identified five complications of diabetes which are treatable and preventable.

These include visual impairment, adverse outcomes of pregnancy, flu complications, kidney complications, and acute coma.

The National Diabetes Advisory Board has recognized that the CDC Diabetes Program has matured and has recommended that it is time to adequately fund the CDC Diabetes Program.

For the last 3 years the CDC Diabetes Program has been funded at the level of about $5.8 million. The advisory board recommends that the money be increased to $9 million. This will allow CDC's 20 project States to be adequately funded and to offer the Diabetes Program in a statewide area.

The board also recommends that the CDC program be expanded to five additional States.

I recognize that at this juncture, there are significant fiscal restraints, but nevertheless, would remind you that among these complications there are significant Federal expenditures. At this point, there is over $400 million spent annually for in-State relief. CDC is one-eightieth of this budget for diabetes control. There was $250 million spent for amputations and some $45 million a year for blindness.

So that this effort at prevention of these complications which the CDC programs offer, I think they're a small investment for what is going to be an increasing cost to the Federal Government, unless something is done to prevent some of these complications. And I would urge that your committee consider the CDC program and fund it at the National Advisory Board level.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Doctor. I appreciate it. Your statement in its entirety, will be included in the record.

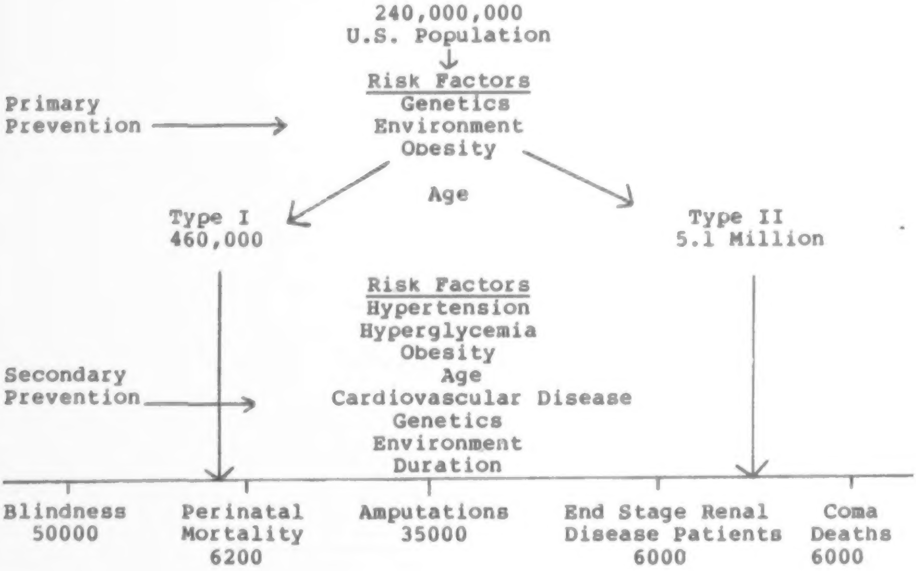
[The statement follows:]

STATEMENT OF LARRY C. DEEB

The Centers for Disease Control (CDC) Diabetes Control Program was established in 1977 upon recommendation of the National Diabetes Commission. The Diabetes Control Program was placed in an environment where no true chronic disease program had ever existed. That environment consisted of a tradition of a federal and state partnership, and a proven record of consensus building within a disease prevention orientation as opposed to simply treatment of diagnosed diseases. This testimony is intented to document the success of the CDC Diabetes Control program, and to demonstrate a clear need for the continuation and expansion of this program.

A model for prevention of diabetes has been developed by CDC and is graphically depicted in the following table:

AN EPIDEMIOLOGICAL MODEL OF THE RISK FACTORS ASSOCIATED WITH DIABETES AND ITS COMPLICATIONS.*


240,000,000
U.S. Population
Risk Factors
Genetics
Environment
Obesity
Age
Primary Prevention
Type I
460,000
Type II
5.1 Million
Risk Factors
Hypertension
Hyperglycemia
Obesity
Age
Cardiovascular Disease
Genetics
Environment
Duration
Secondary Prevention
Blindness 50000
Perinatal Mortality 6200
Amputations 35000
End Stage Renal Disease Patients 6000
Coma Deaths 6000

*Deeb L; Mazze R; Sinnock P; Brimberry J; (In Press).

Certain individuals in the U.S. population are at risk of developing diabetes. The elderly, obese, and genetically predisposed are high risk groups. Some of these develop diabetes. Current data and knowledge do not allow prevention of the development of diabetes, that is, primary prevention. The National Institutes of Health (NIH) and other agencies are funding millions of dollars in research to more fully define principles of primary prevention.

Those who develop diabetes develop either type I (insulin dependent) or type II (non-insulin dependent) diabetes. These people are then at risk of developing the complications of diabetes. Much is known about secondary prevention, that is, the prevention of these complications, but not about preventing the disease itself. This is precisely the area in which CDC has chosen to concentrate its efforts. For the first time the potential exists for the development of a national program to prevent the costly complications of diabetes.

CDC is the public health agency of the federal government and as such has long-standing experience working with state agencies in the delivery of public health care. In 1977 funds became available to establish Diabetes Control Programs in ten states. In 1980 ten additional state-based programs were funded by CDC.

CDC has an established and respected history of liaison with the health care community in both service delivery and academic settings. Because of this, CDC can and does influence medical practice in many areas. The vast majority of the 5.6 million diabetics are cared for by primary care physicians, many of whom look to CDC as an authority.

In the early years of the CDC Program, data were gathered to more fully describe the diabetes problem. In cooperation with the Diabetes Data Group, CDC was able to provide the National Diabetes Advisory Board with necessary information about the morbidity and mortality associated with diabetes in order to describe the diabetes problem.

In its 1982 annual report, the National Diabetes Advisory Board estimated that 5,600,000 Americans are directly affected by diabetes. It has also been estimated that the number of people with diabetes will double every fifteen years; people with diabetes are 25 times more prone to gangrene, 17 times more prone to kidney disease, and twice as likely to have heart disease. Because of these complications, the life expectancy of the diabetic is approximately one-third less than the general population.

These numbers, which have gained widespread acceptance as accurate, document the enormous problem created by diabetes. The tragedy is that many of these complication, the human sufferings, and the costs to society are readily preventable with current knowledge.

The CDC Diabetes Control states have also confirmed the critical importance of patient education for persons with diabetes. Using the consensus of diabetes experts, a CDC project state, Maine, was able to convince Blue Cross to reimburse costs to those patients participating in a field test and evaluate outpatient education. To none of the experts' surprise, the venture was found to be very cost effective. CDC will co-sponsor a workshop on reimbursement this fall at Airlie, Virginia seeking a further consensus on this area.

In June 1980, the CDC and the National Diabetes Advisory Board managed to pull the diabetes community into a new era. A consensus was reached among the diabetic community on the controversial issues of blood glucose control and prevention of complications such as blindness and amputations. In 1980, it was agreed that while questions concerning the benefits of glucose control must be addressed in the research area, currently available knowledge and treatment offers hope for prevention of premature death and devastating complications for those with diabetes. Indeed, five complications were identified, blindness, amputations, perinatal morbidity, renal disease and ketoacidosis, which can be prevented with currently available knowledge and treatment. The Advisory Board commissioned the development of a

Guide for the prevention of these complications. CDC field tested the document and now is charged with distributing concise guidelines that can be easily implemented in every physicians's office in America. Given adequate resources for professional education and distribution of these guidelines, people with diabetes will have the opportunity to avoid the dreadful complications of diabetes. The savings of lives and money will be enormous.

Over the last seven years CDC has made this incredible progress in identifying, refining, implementing and obtaining national consensus for preventive diabetes control activities on a very spartan budget. The budget has not changed in 3 years; nor has the number of state programs grown. The lack of expansion has been appropriate during the early years of the Program because CDC was learning and refining the techniques of diabetes control. There is still much to learn, but the knowledge now available about the preventable complications of diabetes demands immediate diabetes control program expansion. The Advisory Board recommends five new states. This is the bare minimum. All recognize the fiscal realities of the times, but the Congress must invest in a cost-effective prevention approach to diabetes control. The current habit of trying to cure disease after it occurs does not work. For example, the diabetes fraction of end stage renal disease (ESRD) cost alone, much of which is preventable, is over 80 times the current CDC budget. The ESRD budget certainly has not been stable for the past 3 years.

I encourage you to critically look at the CDC diabetes program and its progress. The program has forged a consensus for prevention. As we speak today some 27,000 physicians are learning about diabetes and the prevention of its complications partly as a result of this consensus. CDC needs to continue its present efforts and is ready to expand and offer the benefits of its programs to people who have diabetes in states that do not currently receive direct support from CDC.

STATEMENT OF DOUGLAS S. LLOYD, M.D., M.P.H, COMMISSIONER, DEPARTMENT OF HEALTH SERVICES, STATE OF CONNECTICUT

PREPARED STATEMENT

Senator WEICKER. Dr. Douglas Lloyd, commissioner of health for the State of Connecticut and commissioner for the department of health services.

At this time, your complete statement will be made a part of the record.

[The statement follows:]

STATEMENT OF DOUGLAS S. LLOYD

My name is Douglas S. Lloyd. I am a physician and the Commissioner of the Connecticut Department of Health Services. I am speaking to you today, however, as President of the Association of State and Territorial Health Officials, a national organization representing 57 Directors of Health throughout the nation.

I am here today because the members of my organization are deeply concerned about proposed cuts in the national health budget.

Let me begin with the Preventive Health and Health Services Block Grant. I don't think anyone can deny that prevention is one of the great bargains in health care in America today. For the amount of money expended, we get an enormous pay back in terms of lowered treatment costs later because the diseases were, literally, prevented.

Many states, including Connecticut, concentrate on reduction of four primary risk factors: smoking, excess dietary fats and sodium, physical inactivity and high blood pressure. The results of programs on these four factors have been so impressive that ASTHO believes the appropriation for Prevention should be increased ... and would still be cost-effective.

Other preventive programs worthy of your support include the development of the emergency medical system, fluoridation of municipal water supplies, rape prevention programs and training of home health aides.

It comes down to this: In the United States today, we spend almost one thousand, four hundred dollars per capita for curative services. By comparison, the amount we spend on prevention is small change. ASTHO recommends that the Preventive Health and Health Services Block Grant be scaled so that we are spending 50 cents per capita. That would amount to $115 million in 1985. However, realizing the fiscal constraint we are all under, and the action of the Labor and Human Resources Committee in setting

$98 million as the authorization for Fiscal Year 1985, we urge that you take this $98 million as the minimum funding level for the Preventive Health and Health Services Block Grant. And every penny of it, I can assure you, would be paid back eventually by reducing curative expenditures.

Second on my list of concerns today is the budget of the Centers for Disease Control in Atlanta. Rather than the proposed cut of $10 million, for this essential organization, ASTHO strongly supports full funding.

I can personally attest, as can every ASTHO member, that CDC is one of the mainstays of state health departments. They provide us with consultation that is almost impossible to find elsewhere. They give us program support in areas we could never afford singly; they provide direct assistance and laboratory back-up with a level of expertise that is unobtainable, generally, at the state level.

I might also mention that the CDC provides epidemiological advice to our allies and to third world nations on a regular basis at a very low cost. It is one of the best ways I can think of to make friends around the world. Your support of the full CDC budget is urgently recommended.

Incidentally, I know that there are proposals to provide some additional funding for CDC via the imposition of User Fees to the states. Logical as this may sound, we at ASTHO believe that the result will be important tests left undone, important epidemiological investigations unfinished. The states simply cannot afford this added cost. In the long run, we fear that User Fees will undermine the necessity for and effectiveness of the Centers for Disease Control. The nation has a responsibility to back up the efforts of the individual states with the sort of support CDC offers. When we refuse to accept that responsibility, we lower the quality of public health services throughout the United States.

Before I leave the subject of the CDC, I wish also to comment on the significant loss of CDC positions inherent in the budget document. Staffing at the Centers is already at a low level and should be increased. In plain English, imposing personnel ceilings at this time is tantamount to impounding program funds.

In Connecticut, the subjects of dioxin, EDB, AIDS and Agent Orange come up daily. We NEED the expertise of the CDC on these issues. We regard control of positions as nothing more than an insidious way of weakening essential program support.

In regard to CDC programs, ASTHO would recommend a funding level of $54 million for the immunization program.

As you all know, DPT shots, part of the Well Baby Program, have all but eliminated three dreaded childhood diseases. They are required across the country now as a requisite to public school admission. However, federal funds do not pay for the vaccines.

Two years ago, the cost for a dose of DPT was thirty cents. The following year, it more than doubled, rising to 65 cents. Now it has tripled. The cost today is 98 cents per dose at two of the three manufacturers. The third is charging $2.33 a dose.

To ask the states to absorb these soaring costs and to maintain immunization levels is to place an intolerable burden on one of the finest programs in the country.

Now I would like to turn to the Block Grant for Maternal and Child Health Care. These are the monies that support health care for crippled children, infants and their mothers. In 1983, the MCH block grant, including the Jobs Bill, was $483 million. The budget last year was $398 million. This year there is a proposed increase of about 2% -- less than inflation.

In view of the fact that money spent on MCH can be counted on to result in Medicaid savings because early care for mothers and babies reduces the incidence of serious illness later, this seems like a short-sighted approach to effective funding. Also, last year's funding under the Jobs Bill which supported some MCH programs has now been expended and will no longer be available.

For these reasons, ASTHO urges a return to the 1983 funding level of $483 million.

In addition, full funding for food supplements for Women, Infants and Children must be maintained as a priority.

I know that I have used up most of my time. If there were more, I would certainly go into detail about some other equally essential programs, among them, public health education -- which, again, is an effective way to spend money to prevent later skyrocketing health care costs.

NIOSH, a program in occupational health, a sadly neglected field, and ADAMHA -- both also should be protected. However, I am sure that other witnesses will go more deeply into those programs and their needs.

ASTHO would also like to acknowledge the wisdom of the Committee last year in requesting data from the states. We urge that you once again address this issue so that the ASTHO reporting system can be maintained.

I would like to close on a pleasant note, and so I have saved until last, our pleasure at finding that biomedical research is being recognized by the Committee as a valuable part of health care. Your support there is truly appreciated. Thank you.

Dr. LLOYD. Mr. Chairman, I am Douglas S. Lloyd. I am a physician and the commissioner of the Connecticut Department of Health Services. I am speaking to you today, however, as president of the Association of State and Territorial Health Officials, a national organization representing 57 directors of health throughout the Nation.

I am also here because the members of my organization are deeply concerned about the proposed cuts in the national health budget.

Let me begin with the preventive health and health services block grant. I don't think anyone can deny that prevention is one of the greatest bargains in health care in America today. For the amount of money expended, we get an enormous payback in terms of lowered costs of treatment, because the diseases were, literally, prevented.

Many States, including Connecticut, concentrate on reduction of four primary risk factors: Smoking, excessive dietary fats and sodium, physical inactivity, and high blood pressure. The results of these programs on these four factors have been so impressive that ASTHO believes the appropriation for prevention should be increased and would still be cost effective.

Other preventive programs worthy of your support include the development of the emergency medical system, fluoridation of municipal water supplies, rape prevention programs, and training home health aides.

It comes down to this: In the United States today, we spend almost $1,400 per capita for curative services.

Senator WEICKER. How much is that?

Dr. LLOYD. $1,400, and there are some indications that it may be as high as $1,600 in Connecticut. That is for curative, sickness care.

By comparison, the amount that we spend on prevention is, indeed, small change. ASTHO recommends that the preventive health and health services block grant be scaled so that we are approximately 50 cents per capita. Contrast that with the figure I just gave you. That would amount to $115 million in 1985. However, realizing the fiscal constraint we are all under, and the action of the Labor and Human Resources Committee in setting $98 million as the authorization for fiscal year 1985, we urge that you take this to $98 million as the minimum funding level for the prevention grant. And every penny of it, I can assure you, can be paid back eventually by reducing curative expenditures.

Second on my list of concerns today is the budget of the Centers for Disease Control in Atlanta. Rather the proposed cut of $10 million for this essential organization, we support full funding.

I can personally attest, as every ASTHO member can, that CDC is one of the mainstays of health departments. They provide us with consultation that is almost impossible to find elsewhere. They give us program support in areas we could never afford singly; they provide direct assistance in laboratory backup with a level of expertise that is unobtainable, generally, at the State level.

I might also mention that the CDC provides epidemiological advice to our allies and to Third World nations on a regular basis at a very low cost. It is one of the best ways I can think of to make friends around the world. Your support of the full CDC budget is urgently recommended.

Incidentally, I know that there are proposals to provide some additional funding for CDC via the imposition of user fees to the States. Logical as this may sound, we at ASTHO believe that the result would be important tests left undone, epidemiological investigations left unfinished.

Before I leave the subject of the CDC, I wish to comment on the significant loss of CDC positions inherent in the budget document. Staffing at the centers is already at a low level and should be increased. Imposing personnel ceilings at this time is tantamount to impounding program funds.

As you know, Senator, the subjects of dioxin, EDB, AIDS and Agent Orange come up daily. We need the expertise of the CDC on these issues. We regard the control of positions as nothing more than an insidious way of weakening essential program support.

In regard to CDC programs, we recommend a funding level of $54 million for the Immunization Program.

As you all know, DPT shots, part of the Well Baby Program, have all but eliminated three dreaded childhood diseases. They are required across the country now as a prerequisite to public school admission. However, Federal contracts have not been used to purchase the vaccines.

You've heard this mentioned here this morning, 2 years ago, the cost for a DPT shot was 30 cents. The following year it was doubled, now it's tripled. It's 98 cents per dose at two of the three manufacturers. The third is charging $2.33 a dose.

Senator WEICKER. Why do you think that is? I was interested in the previous statement on that? Why does it increase so rapidly?

Dr. LLOYD. I'm not sure. In some cases, I think it's a rather exclusive vaccine on the market.

Senator WEICKER. Who makes it?

Dr. LLOYD. Merck, Sharpe & Dohme.

So the increases have gone up rather drastically.

Senator WEICKER. I'd like to have staff contact them and find out why their increases have gone up so recently.

Dr. LLOYD. I don't think the technology has gone up that much.

Senator WEICKER. Well, they invented it a decade ago. Now the learning curve should be going down. Obviously, there is inflation involved somewhat, but I'd like to know.

Dr. LLOYD. I'd like to turn for a moment to the block grant for maternal and child health care. These are the moneys that support health care for crippled children, infants, and their mothers. In 1983, the MCH block grant, including the jobs bill was $483 million. Last year the budget was $398 million, and then there was an increase proposed of about 2 percent—less than inflation.

I think we all recognize that moneys spent on MCH can be counted on to result in medicaid savings because early care for mothers and babies reduces the incidence of serious illness later on. This seems like a rather shortsighted approach to effective funding. Also, last year's funding under the jobs bill, which supported some MCH programs, has now been expended and will no longer be available.

For these reasons, ASTHO urges a return to the 1983 funding level of $483 million.

In addition, full funding for food supplements for women, infants, and children must be maintained as a priority.

I have used up most of my time. I would like to talk about NIOSH, a program for occupational health, a sadly neglected field.

And we would also acknowledge the wisdom of the committee last year in requesting data from the States.

I would like to close on a pleasant note. I have saved it for last. It's the pleasure of finding that biomedical research funding is being recognized by the committee. And your support there is truly appreciated.

Thank you very much, Senator.

Senator WEICKER. Thank you very much, Doctor.

Dr. LLOYD. Let me just add these two for the record. This gives an explanation of some of our projects.

[The information follows:]

[From Prevention Notes, Issue 1]

Health Risk Assessment

Health risk assessment/health hazard appraisal (HRA/HHA) is a component of "prospective medicine," with emphasis on identifying precursors of illness and injury and controlling them. HRA/HHA programs in use nationally range widely in terms of scientific basis, sophistication and comprehensiveness.

Dr. Lewis C. Robbins, Chief of the Cancer Control Branch of the Division of Chronic Diseases of the United States Public Health Service, founded "prospective medicine" in 1959. Up to that time, the prevailing philosophy of cancer control was based on early detection and treatment. Dr. Robbins believed that, while early diagnosis and treatment are important, cancer could be more effectively controlled through a program of identifying and reducing causes of the disease. Thus was introduced the concept of recognizing and quantifying health risks and reducing or controlling the causes of disease; over time it was extended to injuries and diseases other than cancer.

The following exemplifies how risk factors contribute to causing disease:

- A two-pack-a-day smoking habit doubles the average risk of dying from lung cancer for a 45-year-old individual. If the individual quits smoking, the risk of death from lung cancer returns to average after a 10-15 year period.
- Using seat belts reduces the danger of death and injury from motor vehicle accidents by 60 percent.
- A 50-year old man with uncontrolled high blood pressure has twice the chance of suffering a heart attack as an individual with normal blood pressure. If that person smokes or has a high cholesterol diet, his chances of suffering a heart attack are 8 times higher. If all three risk factors are present in that individual, his chances of heart attack are 12 times greater.

The nation's first public health revolution, characterized by the control of communicable diseases, has proved highly successful. Today the nation is embarked on a second public health revolution directed at chronic disease, the major cause of disability and death in the U.S. In this war on disease, a health lifestyle emerges as a most important weapon, and the HRA/HHA program as an attractive health promotion technique.

The health hazard appraisal has its critics, mainly alleging that scientific evidence is insufficient to document its effectiveness.[1] On the other hand, the Director of the Centers for Disease Control has written:[2]

- "HRA/HHA should not be construed as a panacea to handle the complex medical, environmental, and behavioral problems related to chronic diseases and trauma . . . Behavioral change results, while important, should not be the only criterion by which HRA effectiveness is judged. Perhaps its greatest value is to clarify the immense complexities of biomedical and epidemiological research and present them in a format that is both understandable and relevant to the individual citizen."

In their book, PROSPECTIVE MEDICINE,[3] Hall and Zwemer made this observation:

> "Finally, health hazard appraisal has been shown to stimulate favorable changes in health behavior — particularly in such areas as alcohol habits, body weight, breast self-examination, exercise and seat belt usage."

SPECIFIC OBJECTIVES FOR THE 1990's (As stated in *Promoting Health/Preventing Disease for the Nation)*:

a. By 1990, at least 60 percent of the estimated population having definite high blood pressure (160/95) should have attained successful long-term blood pressure control (140/90 or below).

b. By 1990, the prevalence of significant overweight (120 percent of "desired weight") among the U.S. adult population should be decreased from 10 percent of men and 17 percent of women without nutritional impairment. (In 1971-74, 14 percent of adult men and 24 percent of women were significantly overweight.)

c. By 1990, the proportion of adults who smoke should be reduced to below 25 percent. (In 1979, the figure was 33 percent.)

d. By 1990, the proportion of problem drinkers among all adults aged 18 and over should be reduced to 8 percent. (In 1979, it was about 10 percent.)

e. By 1990, the proportion of adults 18 to 65 participating regularly in vigorous physical exercise should be greater than 60 percent. (In 1978, the figure was over 35%.)

Current Activity:

In general, HRA/HHA programs administered by the nation's health departments are not lengthy, comprehensive or sophisticated, nor do they place heavy emphasis on morbidity/mortality data, quantification of risks or prediction of death. Their primary purpose is to raise the level of awareness regarding the linkage of behavior to disease and death and to encourage the adoption of more healthy lifestyles.

Centers for Disease Control. According to a 1982 survey,* 22 state and territorial health departments are now using health risk appraisal forms developed by the Centers for Disease Control. The remaining states and territories are planning to use health risk appraisal programs in the future according to the survey.

Rhode Island. The Rhode Island Department of Health has developed Wellness Check, a computerized health risk appraisal program. Wellness Check clients complete a questionnaire card concerning their lifestyle habits; their responses are fed into a card reader linked to a microcomputer; immediately they receive a personalized printout rating their health status, detailing the health risks, and recommending interventions. There are both adult and teenage versions.

In Rhode Island, most of the Wellness Check participants have been processed through the "Wellness Wagon", a computer equipped van that has traveled throughout the state. The system provides for immediate comparison of lifestyle profiles among various participating groups, schools, businesses or communities. Program software and materials are being provided to every high school in the state to facilitate customizing health education programs for each school system to meet particular community needs.

Arizona. The Arizona Department of Health Services is conducting two local community health promotion projects, in an urban and a rural site. The program is neighborhood based and focuses on encouraging individuals to accept more responsibility for their own health, the health of their family and their community.

Layleaders in each site were selected to serve on a Health Council which is responsible for planning and implementing the health promotion activities in the community. Involvement of area businesses, health facilities, civic groups and organizations and professionals in each community assures community integration of the project. Among the activities being conducted are: CPR and basic first aid training, home safety assessment, establishment of a neighborhood health resource center, health risk appraisal and lifestyle counseling, health fairs and senior needs assessment.

New Jersey. The Lifestyle Improvement for Employees Project (LIFE), developed by the New Jersey Department of Health, is responsible for organizing employee intervention programs for smoking, exercise, weight control, nutrition and stress in the State Department of Health. LIFE also provides assistance to other State agencies (Education, Higher Education, Treasury) in establishing similar employee health promotion activities. Ten additional State agencies have expressed interest in LIFE.

Oklahoma. In Oklahoma businesses and industries have eagerly participated in the Oklahoma State Department of Health's Lifestyle seminars, health hazard appraisals and blood pressure screenings. Several companies saw a 90 percent participation rate in the prevention programs. Other companies, including Ingersoll Rand and C. R. Anthony, used the lifestyle seminar and health hazard appraisal as the kick-off event for their own "brown bag" health seminars. Diamond Crystal Salt Company and Goodyear Tire Company were among businesses that were so impressed with the need for healthy lifestyles after participation in this program, that they developed exercise programs for their employees and now provide incentives to stop smoking and lose weight.

Connecticut. In Connecticut the State Health Department uses health education methods to reduce four risk factors: smoking, excess dietary fats and sodium, physical inactivity, and high blood pressure. Through these statewide efforts conducted by the Department as well as grants to local agencies, Connecticut has noted the following achievements:

- The number of public high schools in the state permitting student smoking areas has declined for the first time in 10 years. The Department is forming coalitions with the state's three major voluntary health agencies to persuade more local school boards to rescind student smoking privileges.
- Approximately ⅓ to ½ of those served by local grants were at risk for one or more of the four factors. Evaluation measures collected at the beginning of programs by six local projects for clients served indicated that: 35% smoked; 36% consumed excess sodium and fat; 47% did not exercise on a regular basis; 30.7% had borderline or elevated blood pressure and 22.8% were not aware of the blood pressure status.
- Over 100 Fair Haven senior citizens were taught to reduce sodium and fat in their traditional ethnic holiday recipes by a local grant-funded nutritionist. The area served is a part of New Haven which is poor and medically underserved and over 50% of the seniors had high blood pressure or heart disease.

Analysis:

The battle for improved health behavior is being won. Fewer people are smoking cigarettes, more are exercising, more have their high blood pressure under control, more are eating healthier diets, and more are wearing seat belts. Although much has been accomplished, so much more can be done with additional resources. Increased funding will allow states the flexibility to undertake different intervention strategies, document the effect of these strategies, expand target populations and bolster program efforts aimed at early intervention.

Block Grant Impact:

The Preventive Health and Health Services Block Grant of $88.2 million inadequately supports this effective tool for health promotion and disease prevention. The appropriation for 1985 should be increased to at least $115 million. The per capita cost for health care in the United States is $1400. Surely, the nation can pay $.50 per capita to prevent illness and injury.

Bibliography:

[1] Wagner, Edward H., MD, MPH, Beery, William L., MPH, Schoenbach, Victor J., MSPH, Ph.D., and Graham, Robin M., MSPH — AN ASSESSMENT OF HEALTH HAZARD/HEALTH RISK APPRAISAL, American Journal of Public Health, April 1982, Volume 72, Number 4.

[2] Foege, William H., MD — ONGOING RESEARCH TO IMPROVE HEALTH RISK/HAZARD APPRAISAL, American Journal of Public Health, September 1982, Volume 72, No. 9.

[3] Hall, Jack H., AB, MD, Zwemer, Jack D., DDS, Ph.D., PROSPECTIVE MEDICINE, Methodist Hospital of Indiana, 1979.

[4] Blankenbaker, Ronald G., MD, Moore, Ann T., BS — HEALTH PROMOTION AND DISEASE PREVENTION — THE SECOND PUBLIC HEALTH REVOLUTION, Centers for Disease Control, Atlanta, Georgia.

[From Prevention Notes, Issue 2]

HEALTH EDUCATION—RISK REDUCTION

Health Education-Risk Reduction refers to programs intended to encourage changes in personal behaviors and thereby lower the risks of premature death and disability. Health Education-Risk Reduction programs usually incorporate an activity or combination of activities provided to a defined target population which is designed to reduce at least one specific risk factor. Risk factors targeted by these programs may include alcohol abuse, obesity, smoking, hypertension, stress, sedentary lifestyle, lack of seatbelt use.

The need for Health Education-Risk Reduction programs has been well defined in the Surgeon General's Report, *Healthy People*, which has estimated that as much as 50% of mortality in the United States is related to unhealthy behavior or lifestyle. Today chronic diseases and other preventable health conditions, such as motor vehicle accidents, have taken over as leading causes of death. Dramatic reductions of many of today's foremost killers, heart disease, cancer, stroke, diabetes, cirrhosis of the liver and accidents, can be achieved through preventive measures.

Specific Objectives for 1990 (As stated in *Promoting Health, Preventing Disease: Objectives for the Nation*).

Health Education-Risk Reduction objectives are incorporated in the strategies to meet objectives for the 15 content areas outlined in the document, *Promoting Health, Preventing Disease*. The Health Education-Risk Reduction objectives which relate most specifically to the reduction of premature death and disability are found in the content areas, blood pressure control, accident prevention and injury control, smoking and health, misuse of alcohol and drugs, nutrition, physical fitness and exercise, and control of stress and violent behavior.

INTERVENTIONS

It has been shown that Health Education-Risk Reduction programs which employ a variety of intervention methods tend to be most effective in modifying risk factors. The use of multiple intervention methods has shown statistically significant results in projects dealing with smoking, compliance, blood pressure and cholesterol. The use of multiple intervention methods has been successful in community and patient settings.

A particularly important example of the use of multiple methods is the North Karelia project. This comprehensive community risk reduction project was targeted towards a population of 180,000 residents of North Karelia County in East Finland. The goal of the project was to reduce morbidity and mortality from cardiovascular disease. Methods used in this project included:

- Improved preventive services to identify persons at abnormal risk of disease and provide appropriate medical attention;
- Information to educate people about their health and how it can be maintained;
- Persuasion to motivate people to take healthy action;
- Training to increse skills of self-control, environmental management and social action;
- Community organization to create social support and power for social action;
- Environnmental change to create opportunity for healthy actions and improve conditions unfavorable to health.

At the end of a five year period, smoking, serum cholesterol and blood pressure showed significant reductions in North Karelia when compared to a reference area. In addition, a clear reduction in pension disability payments for cardiovascular disease was observed in North Karelia compared to a reference area. Pension disability data suggested that payments of over four million dollars may have been avoided through the project's activities which cost less than one million dollars.

School based Health Education-Risk Reduction programs can result in significant changes in knowledge and attitudes. These results occur when the health education program is comprehensive (not limited to one disease or behavior), when teachers have been properly prepared and when the curriculum is geared to the appropriate developmental level. Changes in knowledge and attitude have been demonstrated repeatedly in the School Health Curriculum Project. While achieving changes in health behavior in a school setting is difficult, it is attainable. Statistically significant decreases in smoking behavior have been demonstrated in several settings.

CURRENT ACTIVITY

Massachusetts. The Massachusetts Department of Health has focused on family violence as a target of prevention activities. In general, preventive approaches to family violence are rare and are largely ignored due to the more immediate demands for crisis intervention services. The Department's activities are concentrating on adolescents, a population which is in the early stages of learning how to respond to stress in their lives. In FY 1983, the Department contracted to develop a curriculum for use in schools and community settings which would decrease the prevalence of family violence through increasing the abilities of individuals to identify and cope with stress by constructive and non-violent means." In FY 1984, this curriculum will be pilot-tested, evaluated, refined and distributed to educational and community organizations.

South Carolina. A major emphasis of the South Carolina Health Awareness and Promotion Initiative is to facilitate and extend the activities of the South Carolina Primary Prevention Council. This group is a multi-agency coordinating group dedicated to preventing disease and improving the health of the people in the state. The Council is serving as a key mechanism for communication and cooperative development of health education/risk reduction activities. Significant accomplishments of the Council have included the Governor's Conference on Health in South Carolina, the Governor's Regional Conferences on Health Promotion at the Worksite, the Governor's Health Promotion Awards for exemplary worksite health promotion programs, and the annual Carolina's Primary Prevention Conferences. At the request of the Governor, the Council has recently completed the development of a Prevention Plan for Health and Human Services. This plan identifies major problem areas, recommends needed intervention strategies, and sets forth a comprehensive prevention policy addressing both health and human services. The purpose of the plan is to accelerate prevention efforts in both the public and private sectors.

Arizona. The Arizona Department of Health has developed an Asthma Project to inform the public about the misconceptions on asthma. The Asthma Programmed Text for Educators, entitled "The Breathing Tree" was designed to give basic information about asthma, its effects on the child both physically and psychologically, the warning signals, triggers, medications, and preventive actions. The programmed text is accompanied by a two hour in-service training for teachers that will emphasize specific materials and help teachers share their experiences dealing with the asthmatic child.

Pennsylvania. The Pennsylvania Department of Health is providing funds to 14 school districts for implementation of the School health Curriculum Project. This project a comprehensive health education curriculum for K-7 grades. The results of over 24 evaluation studies indicates that it is effective in improving the health knowledge, attitudes and practices of students. A recent longitudinal study suggests that the curriculum also has a positive impact on parental health behaviors such as smoking. Due to lack of funding, the Health Risk Reduction Program can only fund 14 out of the 500+ school districts in Pennsylvania.

Utah. The Family High Risk Program (FHRP) is a collaborative effort between state and local health departments, university clinicians and researchers, private foundations and physicians. Using a pedigree approach, 10,000 families per year will complete a Health Family Tree Questionnaire. This will identify approximately 6,000 to 12,000 individuals each year at greatest risk for development of heart disease, stroke, diabetes and certain types of cancers before the onset of disease.

In FY' 1984, 82 percent of families contacted agreed to participate in the program. In the first six months of implementation, 5,729 Tree questionnaires were analyzed, yielding over 1,000 families with strong tendencies for early heart attack, high blood pressure and diabetes.

Alabama. Because of the limited resources in Alabama, the Department of Health coordinates prevention programs with other agencies which have similar goals and purposes. It has approached health promotion through mass media, printed materials and exhibits in an effort to reach larger audiences with fewer staff. A directory of health education programs to facilitate cooperation among agencies was compiled and distributed.

In addition, promotion of the use of clinical services of the Family Health Administration was achieved by printing public service information on two monthly checks of 55,000 recipients of Aid to Dependent Children.

ANALYSIS

Given that approximately 50% of mortality is related to lifestyle, a greater proportion of federal health resources should be directed to health education and risk reduction programs. Currently a miniscule portion of the Federal health care dollar is allocated to prevention. State Health Departments need increased funds to continue Health Education-Risk Reduction programs. If the 1990 objectives for the nation are to be met, increases in the Preventive Health Block Grant are necessary.

RAPE SERVICES TO VICTIMS AND RAPE PREVENTION

Rape is purely a crime of violence. It is related to sex only in that the act of sexual intercourse is the means by which the rapist perpetrates the crime. Sex is not the motivating factor, only the chosen mode of expression.

Rape is a crime on the increase, even though it is one of the least reported crimes. The Law Enforcement Assistance Administration estimates that only 20% of all rapes are reported.[1] Consequently, as many as 80% of all rape victims do not report the crime to the police or even seek medical treatment. An estimated half million American women—of all ages, races, and classes—are victims of rape each year. According to the Metropolitan Organization to Counter Sexual Assault in Kansas City, Missouri, every woman can estimate her chances of facing sexual assault at one in four.

For too many people, the word rape conjures up an image of a young woman provacatively dressed, walking alone in an alley late at night. They conclude the victim was asking for it and the rapist could not control himself. But rape is not an unsophisticated seduction or a crime of impulse. One study indicates that 90% of gang rapes, 83% of rapes with two attackers, and 58% of solo rapes are planned.[2] One half of all rape cases involve a rapist who knows the victim, either a casual acquaintance or relative.[3]

Rapists keep raping until they are caught. One rapist is often responsible for numerous rapes. To apprehend one rapist may solve a number of crimes and prevent a number of others. Where rapists have been caught, convicted, and incarcerated, FBI Uniform Crime Statistics indicate that 73% of those released were back in prison for the same offense within four years.[4]

This crime traumatizes, humiliates, and degrades its victims. Its shattering effects may leave a victim and her loved ones emotionally scarred for life. In addition, one must consider a negative impact on community life, as rape can ruin property values, kill business opportunities and in general, mark a public location as a place to be avoided forever.

PROGRAM EMPHASIS (According to the National Center for Prevention and Control of Rape, the Services to Victims and Rape Prevention Programs should place emphasis on one or more of the following areas. This list is not all-inclusive nor prioritized.)

(1) The effect of molestation, rape, and incest on the adolescent victim and her/his family.

(2) Community education: The best defense against rape is to be well informed and aware, to dispel the myths concerning rape and to change public attitudes about rape.

(3) Professional education with medical personnel, court personnel, and police. These groups must be trained to deal with rape victims in a sincere and empathic manner. As long as rape victims believe the system is against them, they will be hesitant to report the crime.

(4) Effective treatment programs for rapists: They have certain psychological problems which cannot be corrected by incarceration alone. Remember, three-fourths of them return to prison with four years.

(5) Increased reporting of rape and attempted rape and the apprehension and conviction of rapists.

CURRENT ACTIVITY

According to the Center for Disease Control, 50 states and 7 territories participate and receive Services to Victims and Rape Prevention funds. Only three million dollars was specifically allocated to this program annually. The amount a state receives is determined by the 1980 census population. Because this program is contained within the Preventive Health and Health Services Block Grant, states are given significant latitude to use funds in the ways they determine to be of greatest benefit to their citizens.

Iowa. In Des Moines, the Rape/Sexual Assault Care Center has devised a single, comprehensive program to deal with the criminal justice system, medical examination, and legal investigation. From the time the center was created in October 1974 through June 1976, police clearance rates for rape cases rose from 50% to 69%. Before the program began, charges were filed in only a third of cases where the offender was identified; that figure increased to 75% by June 1976. While only 40% of the cases tried in the pre-project period resulted in conviction, the figure rose to 65% in the first year and to 82% during the second year.

Missouri. In Missouri, the Department of Social Services since 1981 has been reimbursing physicians and hospitals for the cost of a medical rape examination, under a specific set of guidelines. The Missouri program is unique in that the victim does not have to prosecute in order to be reimbursed. The state requires only that a report of the medical findings be sent to the prosecuting attorney of the county where the rape occurred. During the program's first year, only 18 claims were received and paid. During the second year there were 163 claims received. During the first half of the third year there were 98 claims received. The state believes the acquisition and preservation of medical evidence is critical and will provide for a stronger case if the victim decides to prosecute.

Vermont. Vermont's Sexual Assault Prevention and Intervention Program is focused on preventing sexual assault, educating professionals who deal with rape crisis and its victims, and establishing some uniform standards in terms of education and treatment. Currently, statewide bi-monthly meetings with representatives from the various rape crisis centers and community mental health centers are held in order to coordinate work and activities, disperse information and educate. Other education efforts include feature articles in the press, participation in radio talk shows and dissemination of materials to police, probation workers and teachers.

Mississippi. Rape Prevention and Crisis Intervention project funds were contracted to the Mississippi Gulf Coast Women's Center for direct services to rape victims in three counties and for development of a statewide technical assistance program to other rape prevention projects. The Center maintains a crisis intervention service for victims of sexual abuse which provides a 24-hour telephone line manned by center staff and trained volunteers. Services provided to victims include emergency counseling, transportation, and personal support in the emergency room, police station, and courtroom.

Maine. In order to maximize the potential of United Funding, various Rape Crisis Intervention programs in Maine coordinated their efforts and formed the Maine Coalition on Rape. The Coalition, in conjunction with the Division of Health Education conducted a successful statewide conference on rape in 1983. Various health professionals, members of the criminal justice system and the general public attended the workshop. Members of the Coalition act as consultants to each other's organizations and have shared training, workshop agendas, educational and informational resources, and community organizational strategies. The Coalition has proven itself to be an effective and efficient method for focusing health professional, criminal justice and the general public's attention on the issue of rape.

ANALYSIS

Fifty state programs, 7 territorial programs and a federal expenditure of $3,000,000 is a beginning, but this is still an enormous underinvestment for a crime that victimizes the American female population. Rape instills in the victim an acute disruption of lifestyle and coping skills. It affects the victim's loved ones. It exacts an untold social and economic price from the community. At its best, the amount of money each state receives can only supplement existing rape prevention programs and services to victims.

BLOCK GRANT IMPACT

Three million dollars allocated among the 57 states and territories to provide Service to Rape Victims and Rape Prevention is blatantly inadequate to provide an effective and hard-hitting national program. This grant provided less than $37.00 dollars for each reported rape victim in 1982.[5] And for each reported victim, there are at least four unreported cases. More can be done in this area with increased support to the states through the Prevention Block Grant.

[1] According to the data contained in a booklet prepared by Julia Foster of the Abuse, Assault and Rape Crisis Center, and Sgt. Anne Roling of the University of Missouri—Columbia Police Department.

[2] ib.

[3] ib.

[4] U.S. Department of Justice, Federal Bureau of Investigation. Uniform Report on Crime in the United States, Washington, D.C., 1975.

[5] To determine this figure, $3,000,000 was divided by 81,536, the number of rapes reported in the 1982 U.S. Department of Justice, Federal Bureau of Investigation. Uniform Report on Crime in the United States. Washington, D.C.

STATEMENT OF DONALD B. MARTIN, M.D., PENNSYLVANIA DIABETES TASK FORCE

PREPARED STATEMENT

Senator WEICKER. Next we have Dr. Donald Martin of the Pennsylvania Diabetes Task Force.

At this time, your complete statement will be made part of the record.

[The statement follows:]

STATEMENT OF DONALD B. MARTIN

My name is Donald B. Martin and I am Professor of Medicine at the University of Pennsylvania School of Medicine and Director of the Rodebaugh Center for Diabetes Research and Education at the Hospital of the University of Pennsylvania. I am here today representing the Pennsylvania Diabetes Task Force, appointed by Governor Thornburgh to address the problem of diabetes in Pennsylvania. (See Attachment A.) I am testifying in support of the Diabetes Control Program of the Centers for Disease Control (CDC). I am familiar with this program because Pennsylvania is one of twenty states designated by CDC to develop state diabetes control projects. The Task Force is the advisory body to the Pennsylvania Diabetes Control Project.

Diabetes mellitus is a major chronic disease in which there is a disorder of energy metabolism. About 6 million Americans have been diagnosed as having diabetes and as many more may have undiagnosed diabetes. Diabetes is one of the leading causes of death in the United States, as well as a cause of significant morbidity and excessive hospitalizations. Most of the problems of the disease are related to the chronic complications. Diabetics are more than twice as prone as nondiabetics to coronary heart disease and stroke, show a 40-fold higher amputation rate, represent 20 percent of all endstage renal disease patients in hemodialysis programs and constitute one of the major groups of the blind in the adult population.

During the past decade major advances in the treatment of diabetes have enabled us to prevent or reduce the impact of some of the complications of the disease. For example,

- Diabetes is a major cause of blindness. In the United States, about 5,000 new cases of blindness are reported annually. Treatment of proliferative diabetic retinopathy with laser therapy at the appropriate stage of the disease can reduce the risk of visual loss by 60 percent.

- From 17,000 to 20,000 amputations of lower extremities occur in diabetic patients. Appropriate and early invervention with relatively simple medical measures (such as reduction of smoking, hypertension, blood glucose levels and cholesterol--coupled with agressive treatment of foot ulcers and infections) could reduce this number by more than half.
- Infants of diabetic mothers experience disproportionately high rates of morbidity and mortality. If these infants survive the pregnancy, they are prone to respiratory distress, fetal macrosomia (excessive size) and congenital malformations. Careful control of the mother's blood sugar levels during pregnancy can reduce the death rate of these infants to the same level as that in non-diabetic women. Evidence indicates that control of blood sugar prior to and early in pregnancy will equally reduce the rate of congenital malformations.

Unfortunately, these advances in care have not reached the community level. Rates of complications and resulting hospitalizations attributable to diabetes are still high. One reason for the lag is that no one addressed the barriers preventing translation of diabetes medical advances into health care delivery practices until 1977. At that time, the Centers for Disease Control, responding to recommendations of the National Diabetes Commission, used funds appropriated by Congress to initiate diabetes control projects in ten states. By 1980, twenty states were involved. The goal of the CDC Diabetes Control Program is to reduce the morbidity, mortality and costs resulting from preventable complications of diabetes.

The CDC/State partnerships first conducted special studies to identify factors contributing to the problem. In Pennsylvania, for example, 80 percent of the diabetic population is treated by primary care practitioners rather than by diabetes specialists. These physicians, for reasons of time, cost and accessibility, are not current with the latest advances in diabetes treatment--the advances which can prevent or delay complications. Thus, patients who must deal with the disease on a daily basis are not learning appropriate self-management techniques. As a result, during 1980 in Pennsylvania:

- 7 percent of all hospitalizations were for a primary or secondary diagnosis of diabetes;
- the average length of hospital stay for diabetic patients was 14.3 days compared to 7.3 days for non-diabetic patients;
- the direct cost for hospitalizing diabetic patients was $440 million.

The second step of the CDC States was to develop interventions to address the problems identified. In Pennsylvania, for example, the Pennsylvania Diabetes

Academy, a resource core of diabetes specialists, is devising innovative methods to make diabetes professional education geographically and financially accessible to primary care practitioners who treat persons with diabetes. Among the Academy's products are self-study modules on the five reducible complications of diabetes. The practitioner can study the modules on his or her own time, complete an examination, and receive continuing education credits without leaving home or practice. (See Attachment B.)

The twenty CDC states collectively have conducted over 60 special studies and interventions. Although they vary considerably, each is focused on improving the quality of care provided to persons with diabetes, improving patients' self-management skills, preventing complications and reducing hospitalizations.

A number of significant and positive outcomes have already occurred. Results of diabetes outpatient education programs in several states have documented significant reductions in hospitalizations and associated costs.

- In Maine, data on 813 diabetics completing ambulatory patient education programs showed a 39.8 percent reduction in hospitalizations and a 32.2 percent reduction in length of stay. This represents a net savings of $293 per patient. Based on these findings, Blue Cross/Blue Shield of Maine made reimbursement for outpatient education a permanent benefit for its members.
- In Michigan, an outpatient education program reduced hospitalization by 43 percent. Medicare subsequently authorized reimbursement for diabetes outpatient education in all Medicare certified hospitals in Michigan.

Similar reductions in hospitalizations were achieved in Rhode Island and Kentucky.

The CDC central office provides direction and technical support to the twenty project states. Beyond that, CDC has participated in a number of collaborative efforts at the national level which have provided guidance to the project states. These have included:

- an investigation of deaths among patients using insulin-infuson pumps. Because of the major network developed through the twenty project states, CDC was able to investigate reported deaths among these patients. The study showed that insulin pump therapy is not associated with excessive mortality, but that candidates for pump therapy should be carefully selected.
- primary responsibility for dissemination of the National Diabetes Advisory Board's publication: "The Prevention and Treatment of Five Complications of Diabetes: A Guide for Primary Care Practitioners." CDC developed recommendations for use of this document in programs of professional education and is tracking its dissemination to evaluate its effectiveness.

- pilot-testing national standards for diabetes patient education programs. CDC participated with major diabetes organizations of the public and private sectors to develop these standards as a method of ensuring quality education to persons with diabetes. They are being pilot-tested by twelve CDC project states.

In its seven short years of existence, the CDC Diabetes Control Program has begun to grow into a cohesive national activity. It has demonstrated improvements in patient care and documented their cost-effectiveness in the limited localities encompassed by the intervention projects. The program is a model for the development of other chronic disease initiatives. It is an excellent example of federal, state and private sector collaboration. Most importantly, it has created a network for dissemination of new information to both providers and patients.

All of these accomplishments have been achieved with an average state award of $185,000 a year. Such limited resources, however, preclude broader application of successful interventions within each state. Application of these interventions to new states is out of the question.

Based on the advances we have achieved in Pennsylvania and the accomplishments we have observed in other states, the Task Force feels that the CDC Diabetes Control Program has provided (if you will forgive the vernacular) "more bang for the buck" than any public health program of which we are aware. It would be a tragic waste if the experience of the twenty project states were not shared with others and applied in larger geographical areas within and beyond the current states.

The appropriation to CDC for diabetes control has remained at $5.98 million for the last three years. A increase of just $3 million would:

- intensify efforts in the 20 current states by increasing their level of support from an average of $185,000 to an average of $250,000;
- expand the program to 5 additional states at a funding level of $250,000 thus applying the benefits of diabetes control to approximately four-fifths of the U.S. population;
- provide program enhancement and operational research activities necessary to transfer program accomplishments to a wider geographical area and population base.

The dollars are small; the return is already sizeable and shows promise of continued growth. I am here today because the Pennsylvania Diabetes Task Force agrees that the CDC Diabetes Control Program warrants applause for its accomplishments and support for its potential. We join the National Diabetes

Advisory Board in highly recommending an appropriation of $9 million for this program.

Thank you for allowing me the opportunity to present this statement to you today. Your time, attention and consideration are greatly appreciated.

PENNSYLVANIA DIABETES TASK FORCE

Maurice Hertzfeld, Chairman
Hertzfeld Associates
3700 Science Center
Philadelphia, PA. 19104
(215) 382-5400

D. Walter Cohen, D.D.S.
Professor of Periodontics
Dean-Emeritus, School of
Dental Medicine
University of Pennsylvania
4001 Spruce Street
Philadelphia, PA. 19104
(215) 898-1926

Allan L. Drash, M.D.
Professor of Pediatrics
U.of Pittsburgh, School of Medicine
Dir.,Div.of Endocrinology&Diabetes
Mellitus
Children's Hospital
125 DeSoto Street
Pittsburgh, PA. 15213
(412) 647-5174

Estelle Fried
1825 Linglestown Road
Harrisburg, PA. 17110
(717) 232-1287

Steven G. Gabbe, M.D.
Professor of Obstetrics&Gynecology
Dir.,Jerrold R.Golding Div. of
Maternal-Fetal Medicine
Department of OB/GYN
Hospital of the U. of PA.
3400 Spruce Street
Philadelphia, PA. 19104
(215) 662-6912

Catherine Gutowski, R.N.
2822 Davidson Avenue
Erie, PA. 16504
(814) 459-8339

Peter Hearn, Esq.
Pepper, Hamilton & Scheetz
123 S. Broad Street
Philadelphia, PA. 19109
(215) 893-3461

Lewis H. Kuller, M.D., Dr. Ph
Prof.& Chairman, Dept. of Epidemiology
University of Pittsburgh
Graduate School of Public Health
130 DeSoto Street
Pittsburgh, PA. 15261
(412) 624-3054

David A. Lawrence, M.D.
301 S. Seventh Avenue
W. Reading, PA. 19611
(215) 374-2231

Donald B. Martin, M.D.
Professor of Medicine and Director
Rodebaugh Center for Diabetes
Research and Education
Hospital of the U. of PA.
36th and Spruce Streets
Philadelphia, PA. 19104
(215) 662-3924

David A. Smith, M.D.
2601 N. Third Street
Harrisburg, PA. 17110
(717) 782-4130

Myles H. Tanenbaum, Esq.
Kravco, Inc.
234 Goddard Blvd.
King of Prussia, PA. 19406
(215) 337-1250

Nancy Werthmuller, M.S., R.D.
Director of Dietetics
Carbondale General Hospital
185 Fallbrook Street
Carbondale, PA. 18407
(717) 282-1330

Task Force Office:

Pennsylvania Diabetes Task Force
3624 Science Center
Philadelphia, PA. 19104
(215) 823-4813
(215) 222-3297

Executive Director: Nina Berlin

Attachment A

Dr. MARTIN. Good morning, Senator. My name is Donald Martin, University of Pennsylvania, and director of the Diabetes Center at the hospital.

I am a member of Governor Thornburgh's diabetes task force, and it is my role here today to push for the CDC Diabetes Control Program from approximately $6 to $9 million. I am not going to read my testimony. You have it on record.

Let me make three or four points, if I may.

The first is the need is there. You have heard the figures about diabetes being a common disease, and it is.

I would submit to you that one can rarely go to a social professional gathering and talk to people without having someone in the group be aware that you're interested and relate to you that they or a near relative has this disease. It's common.

Equally important is that the metabolic and other complications of this disease are also important. The figures are familiar to you, I'm sure. The commonest cause of blindess in middle life, amputations, renal failure, all are serious complications of a very common disease.

Another point I want to make is that proper treatment makes a difference, and to do this proper treatment, there needs to be transferred instructions. Physicians properly trained can make an enormous impact on the pregnancy situation. More currently, under good care, the outcome for a diabetic pregnancy matches that of nondiabetic patients. I can assure you that 30 years ago starting out in this business, it was dramatically different, so it does make a difference.

And there is the laser beam therapy for eye disease, and examples that go on and on.

Instructions in terms of patients and their care, about their care is also important. Examples from Maine or Michigan show that the number of admissions to hospitals, the durations of admissions, all can be related to—the dimunition can be related to patient instruction.

The point is then that proper care instruction does make a difference.

What is the role of CDC in this area? It takes several roles. In the local area, I can speak for Pennsylvania. From that vantage point, where they have been most helpful in setting up studies to see the problems and pinpointing areas of need. You learn, for example, through their help in Pennsylvania, 80 percent of the patients with diabetes are cared for by practitioners, primary care doctors, doctors that are not necessarily informed, necessarily of the latest advances in diabetes care.

What else have they done? They have helped us with this kind of goal in mind to develop self-help modules for practitioners. They've helped in terms of nurse—nurse practitioner types. Professionals who go to hospitals in areas to teach nursing staff how to teach patients with this disease to make an impact in their care.

On a more national level, they're important in understanding the problems that pump therapy in diabetes and a number of other areas that are outlined in my testimony.

So in summation, my plea to you then is that we need to increase the budget from the $6 to the $9 million level. With this, we'll then allow an increase in each of the 20 States that has the CDC backup to increase from 185,000 to 250,000, will further allow 5 more States to be included in this. We think this is essential as this becomes more and more important in diabetes care in this country.

Nine million dollars is the appropriation that we're pursuing. Nine million dollars is less than one fighter-interceptor. With this kind of money, one can——

Senator WEICKER. Less than one fighter-interceptor? Less than one landing gear on a fighter-interceptor.

Dr. MARTIN. One wheel. With this kind of budget, we hope to have an impact on a sizable percent of the diabetes population in this country.

Thank you, Senator.

Senator WEICKER. Thank you very much, Dr. Martin.

STATEMENT OF LAURA BAILEY, MAINE DIABETES CONTROL PROJECT ADVISORY COMMITTEE, STATE OF MAINE

PREPARED STATEMENT

Senator WEICKER. Laura Bailey of the Maine Diabetes Control Project Advisory Committee.

At this time your complete statement will be made a part of the record.

[The statement follows:]

STATEMENT OF LAURA BAILEY

Maine is 1 of 20 States under cooperative agreement with the Centers for Disease Control to conduct a statewide diabetes control project. The diabetes control project is located in the Maine Department of Human Services, Bureau of Health. Diabetes mellitus is an extremely serious disease typically resulting in chronic and disasterous complications that affect the kidney, eyes, nerves, and blood vessels of the heart, brain and extremities, and the fetus. It is the leading cause of adult blindness in the United States. In Maine, diabetes is 1 of the 10 leading primary causes of death with an estimated 27,000 residents currently diagnosed diabetic and thousands more undiagnosed (in a State with a population of a little over 1 million).

The central component of the Maine diabetes control project is an Outpatient Diabetic Education Program called the Ambulatory Diabetic Education and Followup [ADEF] Program. The goals of the ADEF Program are to assist diabetics in learning the knowledge, skills, and attitudes necessary to achieve and maintain good diabetes control, and to prevent the acute and long-term complications which result in unnecessary hospitalizations for the person with diabetes.

Diabetes patient education is clearly a service that is an integral part of the patient care process. The daily continuous need for patient self-monitoring of blood glucose, insulin and medication adjustment, diet and meal planning, are all integral to diabetes patient care.

Beginning in 1980, the Maine diabetes control project has been involved in a pilot study on third party reimbursement for outpatient diabetic education. Blue Cross/Blue Shield of Maine agreed to reimburse for the ADEF Program on a 3-year pilot basis; medicare and later medicaid agreed to reimburse as a matter of policy.

The program is offered in over 30 hospitals, health centers, and community agencies in Maine. Centers for Disease Control funding enabled the project to assist these health care institutions to develop the programs; third party payment enabled the institutions to maintain them. It should be noted that when the Maine diabetes control project began, such diabetes patient education programs were located in only one hospital, the largest medical center in the State. To date, over 2,700 persons with diabetes have received patient education services through the ADEF Program. Based on the results of the pilot study, the Board of Directors of Blue Cross/Blue Shield of Maine voted on December 20, 1983, to change the status of reimbursement for the Ambulatory Diabetes Education and Followup Program from pilot study to a permanent benefit for its regular members. This in itself is impressive; however, the results of the pilot study indicated a clear cut cost containment result.

The study showed that for those people referred to the program, completing the individualized education plan and followed up 1 year later there was a subsequent reduction in hospital readmissions and thus health care costs. For those participants of the ADEF Program from January 1981–June 30, 1982, the number of hospitalizations decreased from 457, 1 year prior to attending the education program to 310, 1 year after attending the program. Estimated length of stay decreased from 4,191 days to 2,843.3 days. Analysis of followup data for the participants of the study demonstrated a 32.2-percent reduction in hospital days. Taking an average cost for an inpatient hospitalization stay during that time period, this represented a reduced cost of $359,835. Average charge for the ADEF Program was $150 per participant, yielding a cost of $121,950 to educate the 813 diabetics who reported followup data. The net difference is a savings of $237,885 or $293 per patient. This represented a positive cost/benefit ratio of 1:3.

In a time of concern for rising health care costs, this is clearly a case of properly placed resources having a positive effect on health care utilization and subsequent costs.

These figures, of course, reflect only the monetarized cost savings on one set of measures—hospitalizations. The benefits of improved health, productivity, and quality of life that these figures represent is inestimatable.

It is clear that this was made possible through the continued support of Centers for Disease Control funding. However, this represents only a fraction of what would be possible with increased support. Increased support would enable the diabetes control projects to reach many more persons with diabetes with programs such as this one and to address many of the complications related to diabetes.

Ms. BAILEY. Tom Gorham is the chair of the advisory committee, so I am filling in for him. I was the past chair of this committee. I serve on the chair of the American Diabetes Association and serve on the Board of Directors in Maine. I've also helped to start groups for diabetics in that area.

You have Tom Gorham's testimony, so I am just going to highlight some things and maybe give you some examples of what we go through.

On Friday morning, I was at my ophthamologist, and she gave a fluoroscopic angiogram to me, flushing dye through my veins to see why I couldn't see to read from my right eye. She determined that laser treatment would probably help, so yesterday morning I went into 610 zaps on one-half of my retina before I got the plane down here. One of many restrictions after the laser treatment is that you can carry no more than 10 pounds. So I had to get everything I needed for 2 days into this, for less than 10 pounds. That was a challenge for me. But diabetics live with that. The need for laser treatment is not uncommon among people with diabetes. And I have had it for a long time. I have been on the needle now for 33 years, since I was a freshman in high school. It's a constant challenge to live with diabetes. You live in two worlds at once. You live in the outside world with everybody else. And in the inside, you're thinking, am I staying in balances, my insulin, my diet, my exercise, are these all balanced? And then you can get in a stressful situation and it all goes galley west. As a matter of fact, I am wondering what my stress factor is right now. It's dangerous when your blood level is too high; and it's dangerous when it's too low. When it gets too low, you go into a reaction; your brain isn't fed and you don't know what's going on.

Lots of time, people have been arrested for being drunk for how they act. As a matter of fact, once, when my daughter was 4 years old, she recognized these symptoms and saw that I was having this, and she said, "Mommy, you go lay down. You're having a reaction. I'll go get you some candy." And normally, this is what you avoid most of the time but sometimes we have to have it and people look at us and say, "Oh, you're cheating on your diet." And oftentimes, people's thoughts are "I'm not an OK person, there is something wrong with me." Therefore, their attitudes convey this.

Diabetic women are four times more prone to heart disease. We're all very prone toward high blood pressure. Unfortunately, kidney failure, especially after a prolonged period of time is very apt to develop. Twenty-five percent of all people in this country who are on dialysis are diabetic. Foot problems often occur, and far too often amputations result. This is usually because the person with diabetes has not been educated on how to take care of their feet and/or the physician does not know how.

These are just some of the actual and potential problems of the diabetic. Thus, you begin to understand the value and the need for education for the person with diabetes. You also can understand why they often see their cup is half empty rather than half full, and self images are low. Often they lose hope for any kind of a normal, healthy life.

The diabetes control project in Maine has given hope as well as information to many of these people. Life styles have changed radically. In the Augusta area where I live, there is a man named Mr. Johnson, whose son was brain-damaged, because he did not know how to handle his diabetes. His wife died 2 years ago with complications of diabetes. At that time, he was in the hospital with complications and they never expected him to leave. It was about that time that the hospital took on the Diabetes Teaching Program. It took him two times to go through it, but when he was through, he could go home. He could buy his food, prepare, and eat correctly. Keep in balance. He has a blood machine which helps tell him where his blood is. He now can take little bus trips around the country to visit friends and relatives.

I could tell you many other stories like this about how lives have been turned around. We have over 30 sites in Maine, but there are many places that still aren't covered. Blue Cross/Blue Shield has been so impressed with the record of hospitalizations being prevented among people who have had this course, that they have decided it's well worth their money to fund it. Funding this course still leaves a need for money for us, though, because it is important to educate the dieticians and nurses, physicians, and other health care providers.

The knowledgeable diabetic becomes a better consumer. A little over 3 years ago I wound up in the hospital with a staph infection in my toe. The general practitioner, the staff physician, everyone decided it needed to come off. And I said, "Hey, would it be irresponsible for me to ask for 1 month. I will do everything medically. I'll stay off it. I'll do everything medically that I can to try and save the toe." And they said, "OK, but there's no hope."

I want you to know that that toe is now the healthiest toe on my body.

So it is important for us to know what is going on.

Families are also educated under this program. And it's a very important thing, because this disease affects the whole family. In fact, my daughter told me she was 10 before she realized that everybody's mother wasn't diabetic.

Unfortunately, even under the best of conditions, your blood sugar levels go up and down. And sometimes like a roller coaster. When this happens, our emotions go along with it. Thus, the divorce rate is higher among diabetics.

This program yields fantastic dividends in money saved and in the quality of life, for which there is no price tag.

Diabetes is the third leading killer, after heart disease and cancer.

Quality and quantity can be significantly extended with millions of dollars in savings to the taxpayers.

I've been talking about Maine and the 19 other States that are in this program now, but I am concerned about my brothers and sisters who have no opportunity for this kind of education. Ideally, I'd love to ask you for $18 million and cover all 30 States, but we are asking for $9 million. This is to extend to another five States, but to also expand within the States where this kind of education is going on.

Thank you for your time.

Senator WEICKER. Thank you. How does your eye feel? Are you feeling better today?

Ms. BAILEY. Barely. I'm not seeing anything from it yet, but, hopefully, it's going to be better.

Senator WEICKER. Thank you very much for your testimony.

STATEMENT OF HELEN G. KUSHNICK, SAMUEL JARED KUSHNICK FOUNDATION

PREPARED STATEMENT

Senator WEICKER. Next we have Helen G. Kushnick of the Samuel J. Kushnick Foundation.

At this time, your complete statement will be made part of the record.

[The statement follows:]

STATEMENT OF HELEN G. KUSHNICK

On October 13, 1983, our three year old son, Samuel Jared Kushnick, died as a result of acquired immune deficiency syndrome (AIDS) contracted from blood transfusions he had received at the time of his birth in the neo-natal unit at Cedars-Sinai Hospital in Los Angeles, California. Sam's death devastated our family, including his twin sister, Sara.

During Sam's illness, our daughter was ostracized and rejected by a segment of our Beverly Hills community that is well educated and affluent. Lack of public awareness of the correct facts concerning the transmission of AIDS caused these people to panic and to force nursery school administrators to expell Sara for fear she could "contaminate" the other children. Even after the school and parents had been assured by leading pediatric immunologists and the Los Angeles County Health Department that Sara was perfectly healthy, and that AIDS was not communicable by casual contact, the public hysteria persisted and we were forced to place Sara in another school.

We were totally unaware that our son and daughter had received blood while in the neo-natal unit following their premature births. We never saw bags of plasma hanging above our son's isolette. It was not until his admittance to the hospital on September 25, 1983, after ten months of continual illness that was diagnosed as "normal" childhood maladies, that we discovered from his neo-natal hospital records that Sam had been routinely transfused.

As Sam lay dying, certain facts came to light which at first bewildered us. Bewilderment was quickly displaced by anger, and my husband and I vowed to channel our anger constructively, hence my presence here today.

Sam had received 20 transfusions from 13 different donors, administered in dosages of 5 cc to 17 cc at the time of his birth. Since the blood is not typed, the same pint of O-positive blood was administered to a number of other infants in the unit. One other child who was in the neo-natal unit with Sam, and received blood from the same donors, died at the age of eight months from an EBV virus. His death, in 1981, was listed as resulting from complications of prematurity; doctors now believe he died of AIDS. As of this date, as unconscionable as it may seem, only 5 of the 13 donors have actually been tested in the wake of these deaths.

Sam was not the first, but the fourth, premature male to die in Los Angeles during a six-month period as a result of blood transfusion related AIDS. The first was in February of 1983 at U.C.L.A., the second in April and the third in June both occurred at Children's Hospital. The Center for Disease Control in Atlanta has advised us that Sam's death, as well as these other children, are not included in their statistics for, unfortunately, they did not reach the age of five which is a CDC subject requirement.

The first blood transfusion related AIDS case was reported to the CDC in July of 1982. Guidelines for suspect donors were not put into effect until March of 1983, more than nine months later.

When it became apparent that AIDS was a major health problem, the established methods of obtaining funds for clinical research were too slow. In spite of the fact that funding was eventually found for certain AIDS investigations, the funding for Pediatric AIDS problems continued to be nonexistent. This, I believe, is a reflection of the low total dollars, and even lower priorities, given to Pediatrics and to certain NIH institutes which deal with diseases in children (such as Maternal and Child Health). I have learned that an application for research monies may take one or two months to prepare, must await the regular NIH review cycle, and requires a six to nine month lag before money is actually obtained. This means that the identification of a significant problem, such as the AIDS epidemic, is invariable followed with at least a one year delay in the obtaining of funds for the investigation of that problem. This one year delay, coupled with the nine month delay in reporting blood transfusion related AIDS cases, cost my son a timely diagnosis and the knowledge that he was at risk. Could a bone marrow transplant early in 1983 have saved his life? None of us will ever know.

While the National Cancer Institute and the CDC provided early funding and sponsored conferences on specific topics, other NIH agencies which should have responded were slow in doing so. For example, the Heart-Lung Institute and Maternal and Child Health should have been aware that AIDS was also a Pediatric and blood transfusion problem. Communication to the practicing physician was totally inadequate. Most of the pertinent information regarding AIDS was published in the Mortality-Morbidity Weekly Report which had been supplied without charge to any physician. Shortly before the AIDS epidemic, the free subscriptions were discontinued because of budget cuts to the CDC. This decision, in effect, eliminated the most rapid means of communication to the medical community by public health agencies. Practicing physicians and academic physicians were not being correctly informed about AIDS. It is not appropriate that the public and practicing physicians should receive most of their medical information through the news media, which has been the case with the AIDS crisis. Government agencies have not utilized educational media such as television and radio. As a result, the news media has reported its own versions of events which has often been sensational, inaccurate and has provided little public health information. What has prevailed is the mistaken impression that AIDS is a disease confined to the homosexual community.

The Clinical Research Center program at the NIH has reduced funding to all research centers and associated laboratories in recent years, and eliminated five research centers from 1975 to 1981. The remaining centers have not been able to respond to the magnitude of the AIDS crisis.

One area where a correction in the distribution of funds should occur relates to training programs. The NIH sponsors research training fellowships in other institutions and has its own training fellowships. The yearly support for a research fellow at the NIH is in excess of $30,000 while the amount given to medical institutions for the same position is only $16,000. The AIDS epidemic illustrates the hazards of such an approach. The primary patient population, as well as the academic physicians involved in the AIDS epidemic, are concentrated in cities such as New York, Los Angeles and San Francisco. Yet the strong funding for clinical research exists at NIH where there are few patients with AIDS. Having your child critically ill is frightening. It is a nightmare to realize that the doctors caring for him don't know what the latest or correct treatment is and are phoning around the country, educating themselves as they go along.

During Sam's illness, and following his death, my husband and I have been in constant communication with leading pediatric clinical researchers such as Dr. Arthur Ammann in San Francisco, Dr. Arye Rubenstein in New York, and Dr. James Olesky in Newark. Financial support is desperately needed for intensive clinical research in the pediatric immunological area, for there is now a strong indication that there is a close link between AIDS and various forms of cancer. With Congressional help, greater gains will be made in medicine in the next five years, due to the results of AIDS research, than have been made in the last five hundred years. It is our sincere hope that Congress will immediately increase funding and support for the critical clinical research needed.

My husband and I have formed the Samuel Jared Kushnick Foundation in our son's memory in the hope that his short life will prove meaningful, rather than become simply a statistic ignored by the CDC. We shall use the monies contributed to fund clinical research and to educate the general public and the pediatric medical community. We hope to encourage hospitals to immediately establish direct donor programs, and to recommend to persons facing elective surgery that they donate their own blood prior to their operation. Preferred donor programs are particularly important to neo-natal units, pediatric and adult leukemia patients, and to the hemophiliac community.

At the beginning of the AIDS epidemic, most medical observers agreed that an infectious agent was likely. Individuals at risk with regard to AIDS should have been excluded from blood donation several years prior to the current recommendations. If blood is not screened, one donor who is an AIDS carrier can kill thousands. The statistics of low numbers of reported AIDS cases from transfusions in geographically isolated areas must not be used as a reason to defer funding at this time. We must not let special interest groups channel available funding to their institutions for continued studies. We do not need studies on blood recipients; we need clinical research and blood screening programs now. Our national blood supply has been contaminated for the last four years. Guidelines for donors will help; but we must screen blood products now.

It has been proven that a donor does not have to die or to be seriously ill with this disease to transmit AIDS through a blood donation. The CDC has tracked down 40 AIDS cases linked to one carrier which they have known about since 1982. How many of these men were blood donors in the last two years? Since the carrier is not aware of his illness during an incubation period that may exceed three years, he may donate blood six or more times during this incubation period. Multiply this situation by 1,000 such affected donors and suddenly 6,000 lives may be lost. Obviously, if these recipients of contaminated blood, unaware of the disease in their blood systems, become in turn donors, these 6,000 deaths can suddenly become 60,000 or 600,000. It has been estimated by researchers that 5,000,000 Americans may die of AIDS by 1992 if a cause and a cure is not found.

Blood plasma is shipped everywhere in the United States by the Red Cross. This fearful disease is claiming victims everywhere, and is no longer confined to three or four cities or to the homosexual community. While there is now no specific test to detect AIDS in blood, there are supporter tests which, if utilized, could screen out potential carriers at a cost estimated at $15.00 per donor. Certain blood banking facilities are utilizing these tests on an elective basis; the majority are not. The reasoning is that it is not "cost-effective". Sam's hospital bill alone, for the 19 day confinement until his death, was $94,000. The cost for the current medical care for the number of patients now affected by AIDS greatly exceeds the total expenditure for clinical research centers sponsored by the NIH.

On Tuesday, December 27, 1983, the Los Angeles Times reported that, according to George Nemo, NIH chief of blood resources, the NIH would award $1.2 million to fund research and $30 million for a six year study of 4,000 patients who receive blood transfusions. These numbers, I believe, are in reverse order. The ship has sailed. Five years ago a blood study may have prevented the spread of AIDS. Now the dollars are desperately needed for clinical research, with the emphasis on the screening of blood products to make them safe, and a uniform policy must be required for all licensed blood banks regarding the screening of donors and of blood.

Any man, woman or child who has received a blood transfusion in this country in the past five years was and is potentially at risk for contracting AIDS. Unless we see immediate changes in blood banking procedures, your families, as well as so many others in this country, will live in fear of having blood transfusions. This fear can be eliminated. Blood is often referred to as "the gift of life". With proper funding from Congress for clinical research and dissemination of information, we can prevent blood from becoming "the gift of death".

Mrs. KUSHNICK. My name is Helen Kushnick. I thank you for providing time for me to testify. On September 25, 1983, my son was committed to Cedars Sinai. He was turning blue, and 2 days after a lung biopsy was diagnosed as having pheumocystic carinii pneumonia. Five days later after the immunological studies were completed, we were told that he had acquired immune deficiency syndrome, AIDS, and was going to die. Nine days later my daughter, Sams twin sister Sara, was expelled from the nursery school where she and her brother had been enrolled. School administrators, bowing to pressure from a handful of parents, feared she might contaminate the other students. Nineteen days later, Samuel Jared Kushnick, who was not an IV drug user, not homosexual, not Haitian, nor hemopheliac, died. He was only 3 years old. Those 19 days unalterably changed my life, my daughter's and my husband's, because Sam fit into a category shared by every premature baby born in this country, and millions of American children and adults. He had received blood transfusions. From the time he was born on August 19, 1980, until he was discharged from Cedars Sinai on October 4, 1980, Sam had received 20 blood transfusions from 13 different donors. Small amounts, 5 to 17 cubic centimeters, a teaspoonful to a tablespoonful. I wasn't aware then, I am now, that premature babies are automatically transfused, they take blood out for testing, they put it back in.

Sam was the fourth baby to die in Los Angeles during a 6-month period as a result of blood transfusion related AIDS. The cost of his hospital care during that 19 days was $94,000, just the hospital bill. That does not include the doctors.

In trying to understand why I didn't know, one, about the blood transfusions, and then that my son was at risk from AIDS because of those blood transfusions we started making phone calls. We talked to a number of people.

The Clinical Research Program at the NIH has reduced funding to all research centers and associated laboratories in recent years, and eliminated five research centers from 1975 to 1981. The remaining centers have not been able to respond to the magnitude of the AIDS crisis.

One area where correction in the distribution of funds should occur relates to training programs. The NIH sponsors research training fellowships in other institutions and has its own training fellowships.

The yearly support for a research fellow at NIH is in excess of $30,000, while the amount given to medical institutions for the same position is only $16,000. The AIDS epidemic illustrates the hazards of such an approach.

The primary patient population as well as the academic physicians involved in the AIDS epidemic are concentrated in cities such as New York, Los Angeles, and San Francisco; yet the strong funding for clinical research exists at NIH where there are few patients with AIDS.

Having your child critically ill is frightening. It's a nightmare to realize that doctors caring for him don't know what the latest or correct treatment is and are phoning around the country educating themselves as they go along.

When Sam was in the hospital they made the request for the experimental drug the day that he was diagnosed as having the pneumonia. I think it's called pentanomine and it has to come from the CDC.

No one from the CDC called us, asked for his history. No one showed up. In fact, 3 days later when the blood workups came back the doctor had spent 2 days trying to find somebody at the CDC to talk to to have a live T cell leukemia test done.

My son was a perfect example of someone that they could have used for epidemological research. He had a complete history at the hospital.

The CDC finally showed up after he died, 3 weeks after he died. We had sent blood down to them. We paid for it ourselves. We called a messenger. We sent the blood to the CDC. They lost it.

Two weeks later when I called to find out what the results of the live T cell leukemia test were, they told me that they couldn't find the blood, the doctors at Cedars told me, and by the time they found it, it had been unfrozen; they couldn't run all the tests that they wanted, but they were going to try.

They went back to serology to see if there was any blood left of his in serology that they could send down again to redo these tests. A Dr. Havercoste from the CDC came to see my husband. We had to fight with the hospital to have AIDS put on Sam's death certificate. They didn't want to do it.

I wanted it done because I didn't want it covered up. I wanted people to know that AIDS is not a disease just confined to a specific group of people; and it's spreading, and it's spreading on a daily basis.

The physicians that have been working with the AIDS patients have been fighting with the CDC to get them to redefine their definition of AIDS. I don't know what they're hiding. I don't know what the problem is.

I mean, if we're at war in this country against a disease, then I think we should declare the war and not do ground combat. We've done that too often, skirmishes.

Dr. Havercoste told my husband that if we didn't go public with this that sometime within the next 2 years he would track down the donors. They still haven't tracked down the donors. Only 5 of the 13 have actually been contacted and tested.

Senator WEICKER. Let me say two things. First of all, I really appreciate your coming and appearing before the committee; but let me also reassure you that as far as Congress is concerned, and the administration, we have been willing to give, both last year and will again this year, anything that is needed. That has been made clear to NIH, and it has been made clear to the Centers for Disease Control.

Whatever they need, they can have. So you should know that, that there is no question of any crimp on funding; whatever they can use. All they have to do is ask.

Mrs. KUSHNICK. It's a question of how they're using it, though, Senator.

Senator WEICKER. Well, I gathered that.

Mrs. KUSHNICK. That's the problem. There doesn't seem to be any cohesive effort among the different departments, among the NIH and the CDC and the hospitals.

I asked somebody from the county health department in Los Angeles: What is the procedure? How does CDC notify the State and county agencies when there's an emergency situation, when there's an infectious disease?

And then how does the State and county notify the hospitals? And, more importantly, how do the hospitals notify the practicing physician?

My son went undiagnosed for 10 months because the one publication that the CDC printed, the MMWR, which was dispensed free to physicians, because of budget cutbacks was eliminated. Now, it's perfectly logical to say a physician can spend $100 or $150 a year on a subscription to a magazine that keeps him informed.

Who knows if they even read it? You know, there's a problem with the system.

I really appreciate the time and I know you're limited in time.

Senator WEICKER. Well, I only am in the sense that there's a vote. Again, I think you've raised a very good point and I'm not so sure it has been answered in the testimony that we received today as to who is coordinating this effort.

Mrs. KUSHNICK. Maybe it is time for an outside committee.

Senator WEICKER. I think it's time for us to ask the question: Who's coordinating it? A lot of people are doing it; but I don't have the answer to that question.

Mrs. KUSHNICK. I mean, the first incidences of the increases in Karposi's sarcoma and the pneumocystis carinii pneumonia was 1978. By 1980, 1981 they were pretty sure that an infectious agent was the cause of AIDS.

Why did they wait until 1983 to put guidelines in on blood donations which are ineffective anyway? Something is not right with the system.

Senator WEICKER. Thank you very, very much.

Mrs. KUSHNICK. Thank you, Senator.

Senator WEICKER. I appreciate it.

STATEMENT OF VIRGINIA M. APUZZO, NATIONAL GAY TASK FORCE

Senator WEICKER. Last, we have Virginia Apuzzo of the National Gay Task Force.

Ms. APUZZO. Good morning, Senator.

Senator WEICKER. Good morning. How are you?

Ms. APUZZO. Good. Thank you.

Mr. Chairman, I appreciate the opportunity to testify on behalf of the National Gay Task Force regarding the fiscal year 1985 budget for Public Health Service' AIDS-related activities.

As we heard from Mrs. Kushnick and as we hear daily, AIDS remains a major health crisis in this country. The number of cases has, indeed, tripled over the last year and there is serious question about the definition of the disease and the extent to which we have adequate numbers at all, Senator.

The kind of growth rate makes essential renewed and increased commitment on the part of the Federal Government to finding the cause and cure for AIDS. The response of the gay and lesbian community to this crisis is in the finest tradition of Americans attempting to face a crisis and deal with it collectively and cooperatively.

We have, in every community across the country, organized to provide physical, moral, and financial support for those who have AIDS and for those who are at risk.

As much as my community has done, we cannot do the job alone. That is why, Mr. Chairman, we come before this committee to ask for a higher level of spending on AIDS. We also ask that the committee explore two new initiatives: One, funding of public education and prevention activities by community-based organizations; and contracting for an independent assessment of the Federal response to AIDS.

You mentioned, in relation to the previous testimony, Senator, that the Congress has been more than responsive. All the administration has to do is ask for it and the Congress is committed to being responsive.

I think the key, Senator, is all they have to do is ask for it. I think the question is getting the expression of need on the table. That's something that we feel very strongly about.

Senator WEICKER. Well, out of fairness to the administration—I certainly don't mind coming down on their head; we do it most of the time in these hearings—I have continually asked the Administrators of both NIH and CDC to tell me what it is they need and the committee will give it to them, forgetting what the administration would say.

So I can't do any more than that,——

Ms. APUZZO. I understand.

Senator WEICKER [continuing]. And they've not been constrained, I might add. They've not been constrained to give me anything other than an honest answer to the question.

Ms. APUZZO. I understand.

Senator WEICKER. And that still goes. I want you to know it still goes that we will give them anything they want.

Ms. APUZZO. There is no doubt that over the last several years we have seen a growing commitment on the part of the Public Health Service to address this crisis. During an epidemic, a special case can and must be made for major funding increases even during times of fiscal constraint.

That was recognized by the administration last year when it more than doubled its 1984 budget request within a space of just a few months, from $17.6 million to $39.8 million, with Congress wisely adding nearly $8 million more for a total of $47.4 million.

I wish to parenthetically thank you, Senator, for your wise and caring leadership in making that happen.

A quick review of several of this year's funding proposals will make clear what we feel is a continued need for increased spending levels. The CDC AIDS activities are level funded at $12 million for fiscal year 1985. That does not even allow for increases caused by inflation.

More money and more personnel are needed just to do the basic surveillance in epidemiology associated with the increasing number of cases. Level funding would not even permit CDC to maintain its current scope of activities nationwide; and we've heard eloquently about the necessity to look even more strenuously at the epidemiology that's being done now.

A similar situation exists at the National Institutes of Health. For example, the National Institute of Allergy and Infectious Diseases where 40 percent of NIH AIDS work is being done has the lowest pay line reflecting the number of approved projects that are actually funded in all of NIH, 30 points below the pay line for the National Cancer Institute. The only explanation for this discrepancy is that NIAID has inadequate resources.

One of the most frightening aspects of the AIDS crisis has been the possible transmission of AIDS through blood transfusions. It's a matter of great concern to the gay and lesbian community both as users of the blood-banking system in this country and because the blood issue in particular has been to legitimize increased discrimination against gay men and lesbians.

The Government's efforts in this area have been woefully inadequate. More than 2 years after the issue of transfusion-related AIDS came to the fore, to our knowledge no work on the transmissability of AIDS through blood has been funded, nor have any RFA's on the subject been issued.

We understand that on March 26—more than, again, 2 years after the issue of transfusion-related AIDS came to the fore—the National Heart, Lung, and Blood Institute finally announced $1.13 million in grants to test markers for AIDS; a clear example, Senator, of too little, too late.

Senator WEICKER. Ms. Apuzzo,——

Ms. APUZZO. Yes.

Senator WEICKER [continuing]. I'm going to have to ask you to submit the rest of the testimony only because I'm going to miss a vote. That was the last set of buzzers that rang 1 minute ago.

Ms. APUZZO. Sir, if I may just say, sir, I'd like to underscore the issue brought up by Mrs. Kushnick with regard to an independent outside examination of a plan, not a list of programs but a plan; what they're doing; who's responsible for doing it; how it's being coordinated; and a timely indication to the community at large about what they're finding as they go along.

Thank you. I appreciate the opportunity, Senator.

Senator WEICKER. Thank you very much.

PREPARED STATEMENTS

At this time, we will enter the entire statement of Ralph G. Cantrell, commissioner of the Virginia Employment Commission. Mr. Cantrell was to have represented the Interstate Conference of Employment Security Agencies, but was unable to attend. We will also include statements submitted for the record on appropriations for the Centers for Disease Control.

[The statements follow:]

STATEMENT OF RALPH G. CANTRELL, COMMISSIONER, VIRGINIA EMPLOYMENT COMMISSION REPRESENTING THE INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

SUMMARY

ICESA represents administrators of unemployment compensation laws and public employment offices throughout the country.

AUTOMATION

Data processing capabilities in the state-federal unemployment insurance (UI) and employment service (ES) programs need to be modernized. Computers in more than one-half of the states are more than 5 years old. Of these, about 11 are more than 10 years old. Antiquated machinery threatens ability of UI system to handle recession-level workloads in the future.

UNEMPLOYMENT INSURANCE

Non-personal Services (NPS) - As a result of a $24M reduction in NPS funds for UI in FY'84, hardest hit states are closing local offices and reducing staff. There is no money available for training or capital purchases. Some states will end the year in a deficit position. We urge you to restore this cut in FY 1985.

Continuous Wage and Benefit History Survey (CWBH) - The President's budget request does not include funds for CWBH, a research data base that provides information about the impact of proposed UI law changes on various industries and segments of the work force. The small cost of CWBH ($5-6M) is a bargain considering the data it provides about a program with outlays of $18B.

EMPLOYMENT SERVICE

Inflationary Increase - The FY'85 ES funding level proposed by the Administration is the same dollar level as FY'84. Due to cost increases in salaries, rents, utilities and communications, this will mean a reduction in staff and services to unemployed workers. A dollar increase of $66.6M would permit the system to continue operating at the current level.

Targeted Jobs Tax Credit (TJTC) - The success of TJTC in FY'84 will cause most states to exhaust their administrative funds within the next 30 days. The proposed FY'85 funding level of $20M is the same as FY'84, and will clearly be inadequate. Approximately $45M will be needed in FY'85 to support the increased participation in the program.

Mr. Chairman, members of the Subcommittee, my name is Ralph Cantrell. I am Commissioner of the Virginia Employment Commission and President-Elect of the Interstate Conference of Employment Security Agencies, Inc. (ICESA). ICESA is the organization that represents administrators of unemployment compensation laws and public employment offices throughout the country. Thank you for the opportunity to speak to you today about funding for the state-federal employment security system.

During the recession that just ended, many of us realized how fragile the unemployment insurance system is. It runs for the most part by patch-worked programs on antiquated computers. Making it through the last recession without a major breakdown is a tribute to staff throughout the country who were determined to get the job done whatever the obstacles.

We believe that this time between recessions should be used to prepare for the next one. There has been no substantial investment in employment security data processing since the mid 1970's. Computers in more than one-half of the states are more than 5 years old. Of these, about 11 are over 10 years old. In the computer world, machines older than 5 years are considered outdated; those over 10 years old are considered museum pieces.

This Subcommittee recognized the pressing need for updating UI automation in the FY 1984 appropriation by designating $20M to begin this process and by directing the Department of Labor to report to you on the need for automated systems development in both unemployment insurance and employment service operations and on the availability and adequacy of funds for this purpose. It is our understanding that this report has not been made.

ICESA has collected information about the status of state automated systems. A chart showing the model year of computers in each state is attached. We are now compiling additional data and will be happy to provide it to you and your staff.

There are efforts underway to strengthen the integrity of the UI program both in claims monitoring and tax collections. The President's budget request for UI announces the development of a major set of new initiatives for quality control. Many of these initiatives will likely involve computer cross-match programs that can be effective in identifying potential abuse of the UI system. We are concerned that the quality control initiatives will merely document the existence of errors. This seems fruitless if no resources are provided for improvements. We are committed to operating sound and efficient UI programs; however, the Department of Labor's quality control initiative sounds much like closing the barn door after the cows are out.

Improved data processing capabilities are also needed in order to improve and expand job bank and job matching capabilities of the employment service.

Computers are the basic tools of our trade in matching up unemployed workers and job openings.

It is difficult for us to put a price tag on automation needs. There should be a plan for updating employment security automation over several years, and the cost spread out over that time. It is clear, just from the age of our hardware, that more than the $20M in the President's FY 1985 budget request is needed. This amount is $2.6M below the current level. This year states are competing for the scarce automation resources available even though arbitrary requirements set by the Department of Labor for automation proposals have discouraged some states from applying.

Another funding problem related to automation is the non-personal services (NPS) funding for unemployment insurance. Non-personal services funds are used for ongoing ADP costs and small equipment purchases, office space rental, utilities, supplies, travel, etc. Much of these costs are fixed--they do not vary with the number of claims processed. Because of the shortage of funds this year there is no money available in most states to improve data processing.

The UI system is struggling to deal with a 12 percent NPS cut in FY 1984. This was a surprise to us since the appropriation seemed to be at the same level as FY 1983. It is our understanding that the cut resulted from the change in distribution of ES resources. FY 1984 was the first year that employment service funds were allocated by a statutory formula. Prior to that year, non-personal services funds for UI and ES were pooled. The UI program used a larger share of the pooled funds than the UI appropriation contributed. When the ES funds were withdrawn and allocated separately it left UI with a FY 1984 funding level for NPS that is 12 percent below the level used by the system in FY 1983. Cuts to individual states ranged from 5 percent to over 17 percent. Those states hardest hit are closing local offices and reducing services to try to balance their books by the end of the year. The dollar amount of the cut is approximately $24M. We urge you to restore this amount in FY 1985.

One final item we would like to bring to your attention in the unemployment insurance budget is the Continuous Wage and Benefit History Survey (CWBH). CWBH is a research data base now operating in 17 states. It provides information about the impact of proposed UI law changes on various industries and segments of the workforce.

The Administration's rationale for eliminating funds for CWBH is that the 17 states' data are not nationally representative. The addition of a few more large states would make the data fully representative of the nation and would provide Congress with a valuable tool to show in advance which workers and employers would be affected and how, when federal UI law changes are under consideration.

We urge you to continue funding for the 17 states now participating in CWBH at a cost of $3.6M in FY 1985 and to provide funds to expand the data base so that it is nationally representative. The cost of this expansion has been estimated at approximately $2M. The investment of a few million dollars in a data base that will help Congress and state legislatures make rational decisions about how billions of benefit dollars are paid is a bargain.

Mr. Chairman, turning to another major area within the Employment Security System, the Administration's Program Year 1985 request of $740.4M for employment service functions is the same dollar level that the Congress approved for Program Year 1984. The Administration's request, therefore, does not take into consideration the salary and benefit increases granted to state employees through the action of their legislatures and Governors; nor inflationary increases in rent, utilities and other basic costs of doing business. Further, because much of our system is dependent upon telecommunications, the cost of operating major ES systems, such as job bank, has increased significantly as a result of the break up of AT&T. In some states the increase is two-fold. We are now in the process of collecting this information, on a state by state basis, and will make the results known to the Subcommittee.

We would like to remind the Subcommittee that in FY 1982 the ES system underwent a 24 percent cut in staffing, and was forced to close nearly 500 local, direct services offices. Over the past two years we have adjusted to those severe changes, although productivity has decreased in a number of important areas from FY 1981 levels (see attached chart) when ES staffing was at 30,000. If the system must now sustain another reduction, which is exactly what the Administration's standstill request would do, a significant number of states would again be faced with the same decisions that were before them in 1981--staff layoffs and local office closings. For these reasons, Mr. Chairman, we are requesting your consideration of a nine percent increase for the Employment Service above the Administration's request. This would amount to $66.6M, and allow the national labor exchange system to operate at current levels in the various states.

In addition to the basic labor exchange mission of the Employment Service, it is also legislatively mandated to administer other important programs and activities, critical to the economic improvement of specific segments of the labor force. For example, the Employment Service is the legislatively designated agency to administer the Targeted Jobs Tax Credit (TJTC) Program. Figures (attached) released by the U.S. Department of Labor for FY 1983, reveal over a 100 percent increase in both the issuance of certifications and vouchers from FY 1982 levels. Probably of equal importance is the fact that every target group shared in this impressive gain. However, despite the increased popularity and use of the tax credit by the private sector, the state Employment Service agencies have had to manage the Program with the same $20M over the last three years. The rate of expansion in FY 1984 will, in most states, result in the complete expenditure of administrative funds within the next 30 days. As has been the case in the past, the ES agencies will be forced to utilize scarce resources within their basic operating grant to continue vouchering and certification activities.

For FY 1985, we are requesting $45M from general revenues to administer the program. We believe that this figure is well justified, considering the soaring trend in participation levels, anticipated workload this Summer to support eligible youth, and the current fiscal year experience of having to manage with scarce resources.

A related issue that we want to bring to the attention of the Subcommittee concerns the Administration's plan to change, for the first time, the source of TJTC administrative funding from general revenues to FUTA (Federal Unemployment Tax Act). First, we question the legality of using FUTA funds for this purpose and encourage the Subcommittee to seek an answer to this specific issue. But even more importantly, we strongly object to this change because of the limited FUTA resources which are, by statute, targeted for the Unemployment Insurance and Employment Service Programs. This funding action as proposed by the Administration and if sanctioned by the Congress, would be yet another drain on the FUTA funded Employment Security Administration account.

In addition to the TJTC Program, the Employment Service is substantially involved in the Work Incentive (WIN) Program. We continue to support this vital job placement and training effort for AFDC recipients, and encourage this Subcommittee to allow the Program to continue with adequate resources. For the third consecutive year, the Administration has proposed to eliminate WIN, and we again request your assistance in maintaining the operation.

I would also like to briefly mention to the Subcommittee the statutory role of the Employment Service System as the primary delivery mechanism for veterans' employment services. ES provides services to veterans on a priority basis, and in FY 1983 placed over 450,000 into unsubsidized jobs. In addition, we are actively involved in specialized placement programs for veterans such as the Emergency Veterans' Job Training Program. There are ES staff assigned specifically to serve veterans, i.e., the Disabled Veterans Outreach Program (DVOP) staff and Local Veteran Employment Representatives (LVER's). However, these staff cannot properly serve veterans unless the basic labor exchange system is adequately in place to support their work. A chart is attached that shows the increase in veterans unemployment, compared to non-veterans, beginning in 1982 when the 24 percent cut in ES began to take its toll.

In addition to the above program areas, the Employment Service is a full partner in the shaping of each state's comprehensive employment and training system, by virtue of the Job Training Partnership Act (JTPA). Building upon our responsibilities and record as a labor exchange, and recognizing our strong administrative and operational link with the unemployment insurance system, the ES is actively involved in Title III Programs for dislocated workers, as well as in other areas of the Act that require labor market information and basic labor exchange services. We will continue to coordinate our activities with those provided for in the basic training portions of the JTPA, and are encouraged by developments to date.

Mr. Chairman, as you can see, the Employment Service System does not operate in a vacuum. We are an integral part of the nation's employment and training system, delivering placement support to any individual needing our assistance as well as to those who may have special barriers to employment such as AFDC recipients, veterans, JTPA and TJTC eligibles, and others. We believe that if our system is held in PY 1985 to the 1984 funding level, our ability to fulfill statutory requirements will be severely constrained, and in some states eliminated. Our request is simply that you permit the system to adjust to normal inflationary demands. To do otherwise would impact beyond basic Employment Service operations.

State-Federal Employment Security System
Data Processing Equipment

State	Model CPU#1	*1st Delivery Date	Model CPU#2	1st Delivery Date
Alabama	IBM 158-AP	73		
Alaska	IBM 4341-1	79		
Arizona	NAS 9060	82		
Arkansas	UNIVAC 1100/63	82		
California	CENTRAL			
Colorado	HONEYWELL L66/60	74		
Connecticut	UNIVAC 1100/82	77		
Delaware	IBM 158-3	73		
Dist Columbia	IBM 145	71	IBM 4341-11	82
Florida	IBM 3081-G16	82		
Georgia	IBM 3033-U12	78		
Hawaii	CENTRAL			
Idaho	IBM 4341-11	82		
Illinois	CENTRAL			
Indiana	UNIVAC 1100/82	77		
Iowa	AMDAHL V6-11	73	IBM 158-3	73
Kansas	IBM 158-3	73		
Kentucky	CENTRAL			
Louisiana	IBM 168	73		
Maine	HONEYWELL DPS8/49D	83		
Maryland	CENTRAL			
Massachusetts	SPECTRA 70	65	UNI 1100/44	75
Michigan	IBM IBM-158-MP	73	IBM 4341-11	82
			IBM 158-3	73
Minnesota	IBM 3033-N	80		
Mississippi	AMDAHL 470/V7	78		
Missouri	IBM 158-MP	73		
Montana	CENTRAL			
Nebraska	CENTRAL			
Nevada	IBM 3031-6	78		
New Hampshire	IBM 145-J2	71		
New Jersey	IBM 3032	78	IBM 3081-D16	81
New Mexico	IBM 158-3	73		
New York	IBM 3084	83		
N Carolina	CENTRAL			
N Dakota	HONEYWELL L66/DPS	79		
Ohio	SPECTRA 70	65	IBM 4331-2	80
			UNI 1100/82	77
Oklahoma	HONEYWELL L66/DPS	79		
Oregon	CENTRAL			
Pennsylvania	IBM 3033-MP	79		
Puerto Rico	IBM 370/148	77		
Rhode Island	IBM 158-3	73		
S Carolina	IBM 158-AP3	73		
S Dakota	IBM 4341-11	82		
Tennessee	HONEYWELL L66/DPS	79		
Texas	IBM 3033-MP	79		
Utah	NAS AS-5	76		
Vermont	IBM 4341-P12	82		
Virginia	CENTRAL			
Virgin Isl.	IBM SYS/36	83		
Washington	CENTRAL			
West Virginia	CENTRAL			
Wisconsin	IBM 3033-MF	79		
Wyoming	CENTRAL			

*Data Decision 82 publication or vendor contact

Employment Service Productivity Comparison of Key Indicators*

Fiscal Years 1981 and 1983

Activity	FY 1981	FY 1983	Difference
	(Numbers in Thousands)		
Individuals' Placed in Jobs	3,728	3,214	-14%
Individuals Counseled	1,096	655	-40%
Individuals Tested	819	549	-33%

*USDOL, General Administration Letter No. 14-82, April 22, 1982

USDOL National ESARs Report, FY 1983

TARGETED JOBS TAX CREDIT PROGRAM
VOUCHERS AND CERTIFICATIONS BY TARGET GROUP
FISCAL YEAR 1983

	YOUTH		VETS		EX-CON		HNDCP		CETA		GEN ASST		SSI		AFDC		TOTAL	
	VOU	CER	VOU	CER	VOU	CER	VOU	CER	VOU	CER	VOU	CER	VOU	CER	VOU	CER	VOU	CER
TOT	581795	259309	80808	24141	94545	21929	78683	25412	1130	383	65169	14480	3115	1254	294394	50736	1286947	431182
I	27470	11808	3820	1165	2923	987	3965	1469	40	12	3847	1125	389	179	17927	3667	64121	22400
II	58486	24491	7723	1722	4724	1406	6329	1700	373	70	21959	3338	412	146	33989	4486	140627	39402
III	46247	19152	6775	1759	7152	2343	8331	2482	73	15	11597	3391	239	129	29738	4966	115786	36776
IV	131638	65314	13834	5206	44369	8656	17528	6048	116	61	866	38	389	142	56537	8788	280543	102018
V	110225	41108	20211	4880	12337	2511	17895	5208	270	71	22421	5179	693	253	59337	10044	266254	77179
VI	65677	34573	5285	2310	5680	1564	6623	2308	112	94	308	136	276	124	19430	4498	115843	49072
VII	44200	15653	6559	1740	5083	1386	5495	1796	47	19	1511	404	173	44	9937	2356	79539	25568
VIII	14895	7850	2415	913	1369	552	2261	1030	0	0	475	147	68	36	4869	1782	28003	13154
IX	51139	26024	6403	2353	6839	1594	5888	2029	48	27	1735	626	318	128	30523	7109	130493	43098
X	31818	13336	7783	2093	4169	930	4368	1342	51	14	450	96	158	73	13007	3040	65738	22515

NOTE: Data for Economic Eligibility Determinations made for youth enrolled in Cooperative Education programs are shown in the second portion of this report. The number reported cannot be equated with Certifications actually issued by participating schools and is not, therefore, included in the totals shown. Also shown in the second portion of this report are Vouchers and Certifications for Summer Youth. These figures are included in the totals shown.

REPORT PREPARED THE USES OFFICE OF PLANNING AND REVIEW, DECEMBER 27, 1983

U.S. Unemployment Rate Comparisons

	1983	1982	1981	1980
Veterans (25-39 years of age)	9.4	9.2	6.2	6.0
Non-Veterans (25-39 years of age)	9.1	9.1	6.3	6.0

Source: BLS, DOL Employment & Earnings, Jan.: 1984, 1983, 1982, 1981

STATEMENT OF HARRY TETER, JR., EXECUTIVE DIRECTOR, NATIONAL COALITION FOR EMERGENCY MEDICAL SERVICES

May 1, 1984

The Honorable Lowell Weicker, Jr.
Chairman, Appropriations Subcommittee on
Labor, Education, and Related Agencies
1108 Dirksen Senate Office Building
Washington, D. C. 20510

Dear Mr. Chairman:

The National Coalition for Emergency Medical Services (NCEMS) would like to state its position for the record on fiscal year 1985 funding for emergency medical services (EMS). As you are aware, categorical funding for EMS was eliminated three years ago forcing the program to compete with other programs within the Preventive Health Services Block Grant. Unfortunately, emergency medical services have not fared well in the block grant. Data from fiscal year 1983 indicate that of the 22 states that reported on how they had spent EMS funds, all but one had cut funding for this program. These cuts ranged from 7% to 84% according to the Center for Disease Control. In its report reviewing state implementation of the Preventive Health Services Block Grant, the General Accounting Office states that a number of states had discontinued funding for EMS "because state officials believed it to be a local responsibility."

Mr. Chairman, decreases in federal support for emergency medical services simply do not make sense in light of the program's proven effectiveness. EMS is primarily concerned with the critically ill and injured victims of trauma. Time is critical; a victim treated by an EMS team will receive initial care and be in the definitive medical center within 60 minutes. When an adequate and properly coordinated system is in place, survivability of trauma victims increases dramatically. Eight out of ten persons who would otherwise die in automobile accidents are saved if availed of comprehensive emergency medical services.

However, this extraordinary success rate is applicable only to those areas that have the benefit of EMS availability. Expansion of existing services, creation of new facilities and systems, and establishment of linkage within the EMS network are necessary for optimal implementation. Traditional geographical and political boundaries are irrelevant in most cases. Systems must cover broad areas rather than small localities because victims may require the services of a variety of specialized facilities, such as a shock trauma center, a burn unit or a pediatric emergency facility. Thus, provision of emergency medical services is not solely a local issue. The federal role is particularly significant, because the most effective system requires interstate networking with a coordinated national focus. The federal commitment to supporting the EMS program must be renewed if we are to realize its full potential.

Accordingly, the Coalition strongly supports specific targeted funding for EMS. The NCEMS respectfully requests that the Appropriations Committee earmark 25% of the FY 1985 Preventive Health Services Block Grant funds for emergency medical services. These monies are imperative if new and updated services are to be established.

The National Coalition for Emergency Medical Services appreciates this opportunity to comment. If we can provide any additional information, please do not hesitate to contact us.

Sincerely,

Harry Teter Jr.

Harry Teter, Jr.
Executive Director

STATEMENTS OF WENDY J. WERTHEIMER, DIRECTOR OF PUBLIC AND GOVERNMENT AFFAIRS, AMERICAN SOCIAL HEALTH ASSOCIATION

Mr. Chairman, on behalf of the Board of Directors of the American Social Health Association and our 40,000 members, I thank you for this opportunity to testify on behalf of the Fiscal Year 1985 appropriations for the federal venereal disease programs. As you know, the American Social Health Association is the only national non-profit organization directed solely on the problem of sexually transmitted diseases.

Our organization has been in operation since 1912, and with a very small budget, we are struggling to fill the gap in services and information left by the federal government, in keeping with this Administration's private sector initiative. But, Mr. Chairman, that gap just keeps getting wider and wider and no effort, no matter how well-intentioned, will succeed in combatting this massive epidemic without the full commitment of the federal government.

The phone lines of our VD National Hotline are so jammed by callers in need of information and referral that as many as 80%

of callers are getting busy signals. Our Herpes Resource Center has responded to more than 800,000 requests for information about herpes. People in this country are in desperate need of answers, answers they are unable to get from their doctors, their families, their school nurses, their churches, or even from their local VD clinics.

The epidemics of venereal diseases in this nation are massive, pervasive, and overwhelming. Sexually transmitted diseases affect one out of every 4 Americans between 15 and 55 years of age. Sexually transmitted diseases affect one out of every seven teenagers. Sexually transmitted diseases are the greatest single cause of unintended sterility among women of child-bearing age, causing pathological sterility in 110,000 women each year. Sexually transmitted diseases affect more babies in one year than children affected by polio during the entire polio epidemic. Sexually transmitted diseases cause more than half of all ectopic pregnancies.

As with any infectious diseases, the only real solutions to the epidemics of these diseases are vaccines. At present, no vaccines exist for any sexually transmitted diseases, and given the meager amount of money and the low priority ascribed to research on the diseases, that is not surprising. This year the National Institute of Allergy and Infectious Diseases will devote a total of about $17.5 million on research on all sexually transmitted diseases. In fact, that number may be too high, as the figure includes funds for hepatitis and group B streptococcal infections as well. Some very crude calculations show that this amount works out to less than 50 cents for every patient suffering from a sexually transmitted disease.

Although Congress has directed the Institute through report language to expand its sexually transmitted disease budget, the funding in real dollars has actually fallen. No prevention and control program can be expected to be successful without answers desperately needed from research. After all these years there is still not even a blood test for gonorrhea.

It is beyond my understanding how anyone can find this response to the problem of sexually transmitted diseases an acceptable or responsible one. Personally, I find it unconscionable.

One of the roadblocks is the medical schools. Medical school students are not being trained in sexually transmitted diseases, not in a clinical setting and not in research. A study in the Journal of the American Medical Association found that out of a total of 4,000 available hours in medical training, American medical students receive an average of less than 6 hours of training in sexually transmitted diseases. The result of this lack of training, in addition to misdiagnosis, inappropriate treatment, and further spread of diseases, is that very few young doctors are being attracted into the field of sexually transmitted disease research. When medical schools place very little importance on these diseases, and the National Institutes of Health offers very little support for research or training, there is a vicious circle of neglect and inattention.

I applaud this Committee for its strong support for AIDS research. I know there are those who feel that the government response to the problem was too slow and too small. But quite honestly, I find it remarkable. Our organization wholeheartedly supports large increases for AIDS research. We know only too well what can happen when epidemics are not adequately addressed by the government and by the medical community. More than 20 million Americans have herpes — a sexually transmited disease caused by a virus. The number of people with herpes has increased at least 1000% since 1966. It is impossible to imagine what terrible tragedy could lie ahead if the epidemic of AIDS ever reached such proportions. But maybe it is not so impossible to imagine. We have only to look at the epidemic of venereal diseases. Uncontrolled epidemics increase geometrically. We cannot allow the epidemic of AIDS to increase to the extent we have allowed every other sexually transmitted disease.

As I just mentioned, more than 20 million Americans have herpes. This year it is estimated that 1,200 babies will be infected with herpes at birth, and half of those babies will die. Half of those who survive will suffer permanent neurologic damage. Since 1979, when AIDS was first identified, thousands of babies have died from herpes. This year the National Institute of Allergy and Infectious Diseases spent less than $4 million on herpes research.

There are those who find it unfair of me to compare the devastation of AIDS to the other sexually transmitted diseases. But I do not believe it is really unfair, it is just that the other sexually transmitted diseases have never been understood.

Since 1979, when AIDS was first reported, the American Social Health Association estimates that more than 200,000 babies have died from venereal disease-related ectopic pregnancy. These deaths are not the topic of segments on "60 Minutes" and there is no large political support or organizations for the victims. These are just very sad personal tragedies. The saddest part of all is that they could be prevented. But in fact, the work on AIDS has actually taken away from these other diseases as personnel, resources, and laboratory support havebeen devoted to the AIDS epidemic.

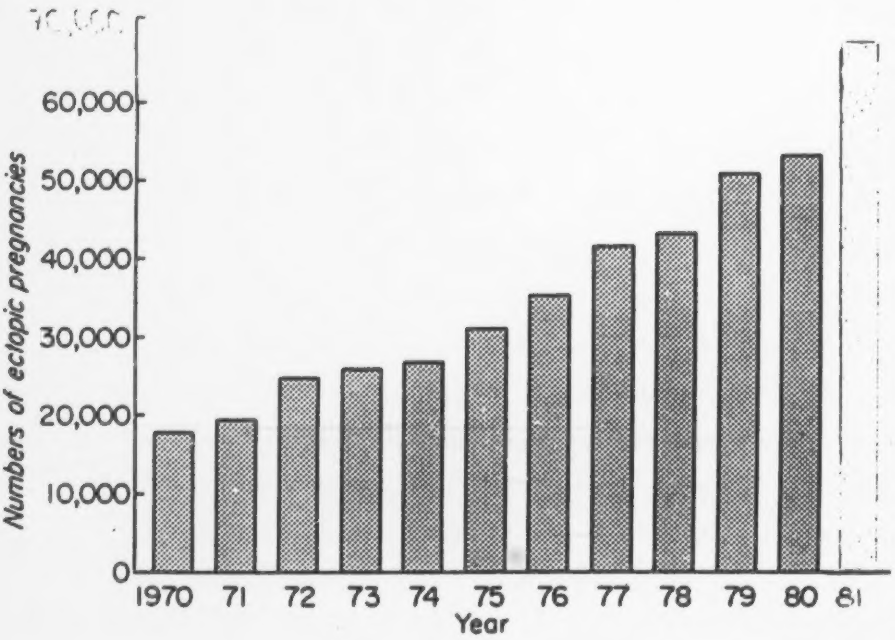
Until a massive infusion of research funds is devoted to sexually transmitted diseases, these diseases and their consequences will continue to ravage our country. In addition to increases in research dollars, training must be a priority of the NIAID. We believe that postdoctoral training as well as Physician Investigator Awards (K11) must be drastically increased. A Study Group on Sexually Transmitted Diseases convened by NIAID in 1980 placed training as its top priority, yet training remains at an abysmal level. In fact, Mr. Chairman, my very small little organization, with a budget which is a fraction of the NIAID, currently supports more research training fellowships in sexually transmitted disease than the NIAID.

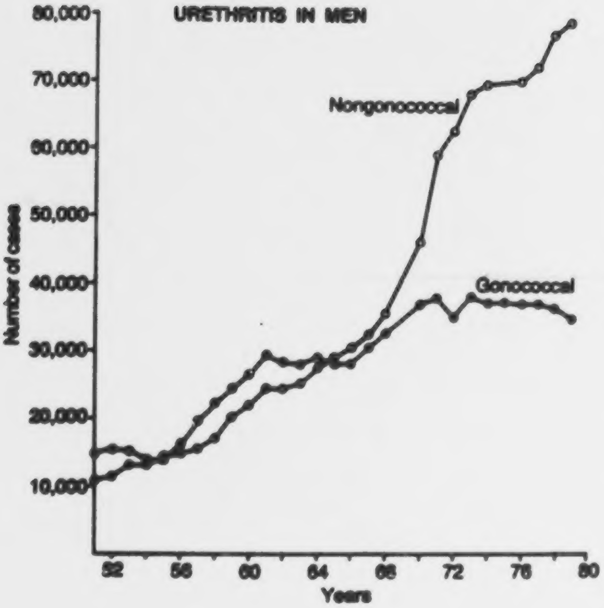
We believe that the NIAID should seek to immediately increase its STD Research Centers to double its current number. NIAID should be actively soliciting applications for research on sexually transmitted diseases, particularly chlamydial infections, genital warts, and herpes as well as clinical, behavioral and preventive studies.

Mr. Chairman, this year at least 35,000 infants will die as a result of venereal disease-related ectopic pregnancy; babies will be killed or brain-damaged by herpes infection; babies will be killed by the ravages of syphilis; and babies will die in the womb from maternal chlamydia infection. Next year those numbers will be even higher. There will be another 600,000 new cases of herpes, and more than 100,000 women pathologically sterilized.

We are grateful, Mr. Chairman, for your support and compassion for this issue. We implore you and this Committee to put an end to fifty years of institutional neglect and provide major funding support for both AIDS research and research on sexually transmitted diseases at the National Institute of Allergy and Infectious Diseases.

ECTOPIC PREGNANCIES IN THE U.S. 1970-1980





Let me begin, Mr. Chairman, by first thanking you and the members of this Committee for the support you have shown for this program in the last few years. We are so very grateful to you for providing funding increases to the VD Prevention and Control program, allowing it to fare somewhat better than many other health programs. We are delighted that the Administration this year has supported categorical funding for the VD program in its reauthorization bill. There are some national public health problems too complex and too massive to just leave to the states.

These last few years, however, have not been easy ones in the area of sexually transmitted diseases. Bear in mind, that these diseases are highly contagious and completely out of control. At this point in time the epidemic of sexually transmitted diseases is more frightening, more widespread, and of greater magnitude than ever before in history. Of all the public health epidemics that plagued nineteenth century society, the only ones left uncontrolled are sexually transmitted diseases. It is incomprehensible to me that we can send men into space with ease and regularity and spend billions of dollars producing ever more powerful weapons of destruction, but babies in this country are still dying of syphilis. The age of Buck Rogers may have arrived, but for one public health problem, we are still locked in a time warp in the last century.

As you know from the testimony of the Centers for Disease Control, the VD control program is almost exclusively focused on syphilis and gonorrhea. In fact, the grants to the states devote approximately 73% of their funds to gonorrhea and 24% on syphilis. With limited resources, the program has been forced to make trade-offs in program priorities, and syphilis cases have again risen as have cases of all the other more than 20 sexually transmitted diseases.

There have been some successes in control of gonorrhea for the first time since the early 1970s when the gonorrhea program began. But new obstacles in gonorrhea control may begin to overshadow that success. There has been a six-fold increase since 1979 in cases of gonorrhea resistant to penicillin. Resistance to antibiotics threatens our ability to control the disease and increases the risk of serious consequences.

Thus, we have a VD control program which has been barely able to make an impact on syphilis and gonorrhea. Today we know that there are more than 20 sexually transmitted diseases which pose a major threat to our nation, particularly to young people, women, and their babies. Not only are there more diseases now known to be sexually transmitted, but there are more people at risk, as the "baby boom" babies are now of child-bearing age, and they are becoming sexually active at younger ages and marrying at later ages than ever before.

Chlamydia is an organism which causes infections in men and women at rates several times that of gonorrhea infection. CDC estimates that at least 3 million cases of chlamydial infections occur annually. In men chlamydia causes non-gonococcal urethritis which can lead to sterility. In women, the consequences of chlamydial infection can be devastating, resulting in sterility or ectopic pregnancy. A study published in 1982 found that stillbirth or neonatal death occurs ten times more often in women infected with chlamydia. Chlamydia also can affect babies, causing eye problems and pneumonia in approximately 182,000 infants annually. Yet only 1 percent of state VD grant funds are spent on chlamydia, and there is no national surveillance of chlamydia infections.

The American Social Health Association has been calling attention to the problem of herpes for many years. In March of 1982 the Centers for Disease Control finally announced officially that an epidemic of genital herpes has indeed been occurring in the U.S. since 1966. Visits to medical practitioners for herpes have increased by more than 1,000 percent. It has been estimated that more than 20 million Americans suffer from herpes, a painful and still incurable disease. Herpes is particularly difficult for women, for whom the disease appears to contribute to a higher risk of cervical cancer. Herpes can be passed to a baby by an infected mother. Of babies infected with herpes, 50% will die, and half of those who survive will suffer permanent neurological damage. The VD program has recently awarded a grant which will provide information about herpes in babies and the extent of the problem, but state VD programs spend less than one percent on herpes, and there is no national surveillance program for herpes.

Probably the least understood aspect of the VD problem in this country is the impact of the diseases on babies. This year more babies will be affected by a sexually transmitted disease than there were children affected by polio during the entire polio epidemic.

Many people choose to ignore the tragedy of venereal disease by thinking that no one dies of VD, but, Mr. Chairman, that simply is not true. There is, in fact, an epidemic of fetal death as a result of these diseases. The rate of ectopic pregnancy in this country has risen alarmingly in the last decade, in direct relation to the rise in rates of sexually transmitted disease. In 1972 there were 17,000 ectopic pregnancies in this country. By 1980 there were

52,000 ectopic pregnancies, and in just one year that rate increased to 68,000 ectopic pregnancies in 1981. No statistics have been compiled yet for the years since 1981, but one can only shudder at what those numbers must be by now. Each ectopic pregnancy results in the death of the fetus, and in serious risks to the mother, as well as large hospital costs. At least half of these ectopic pregnancies can be directly attributed to pelvic infections caused by gonorrhea or chlamydia.

Thus, Mr. Chairman, this year at least 35,000 infants will die as a result of venereal disease-related ectopic pregnancy; babies will be killed or brain-damaged by herpes infection; babies will be killed by the ravages of syphilis; and babies will die in the womb from maternal chlamydia infection.

Another sad result of these diseases is an alarming rate of infertility. This year more than 110,000 women of child-bearing age will become pathologically sterile as a result of these diseases, 50,000 of those women will be under the age of 25. Venereal infections are the greatest single cause of unintended sterility in women of child-bearing age.

Until 1972 the federal VD control program dealt only with syphilis. In 1972 authority was added to initiate control of gonorrhea. In 1975 Congress added authority for the program to prevent and control all sexually transmitted diseases, but at no time since then has the program been given funding necessary to begin to significantly have an impact. With regard to herpes and chlamydia infections the problem has been one of both cost and technology. The cost of diagnosing both herpes and chlamydia is very expensive, requiring tissue culture processes. Herpes remains a disease for which no reliable treatemnt exists, and thus the traditional public health model of diagnosis, treatment, and contact-tracing has been impossible. However, the spread of these diseases can and must be prevented. The VD control program must begin to look at new and innovative ways to finally begin dealing with herpes, chlamydia and human papilloma viruses, which are even more prevalent than any other sexually transmitted disease, and may carry a greater risk of cancer. If traditional methodologies cannot be employed, we must begin to find other ways of being effective.

Luckily research may soon produce some valuable tools for inexpensively diagnosing both herpes and chlamydial infections. These diagnostic tests, when they become available, will make possible some prevention and control of these diseases, and will be a great boon to this program. We are greatly concerned that authorization and appropriations levels allow for substantial program growth when these tests do come available to initiate comprehensive screening programs in the states.

As you can see, Mr. Chairman, penicillin was not the magic bullet. The VD epidemic is complex and interdisciplinary, spanning infectious disease, obstetrics, gynecology, urology, neonatology, virology, oncology, and other specialties. And yet, a study published in the Journal of the American Medical Association which I have included with my testimony, determined that medical students today are woefully undertrained to deal with sexually transmitted diseases. Out of more than 4,000 available medical school training hours, American medical students receive an average of only 6 hours of training in sexually transmitted diseases. The medical establishment has been just as negligent as the government has been regarding this field of medicine. The effect of this is obvious -- poor clinical services, undetected disease, higher disease rates. An additional result is that there is no incentive to encourage young doctors to devote their energies and careers to this field. Why should a young doctor choose to devote a career to this field when there is practically no research money, and his background provided by his medical school barely even covered sexually transmitted diseases?

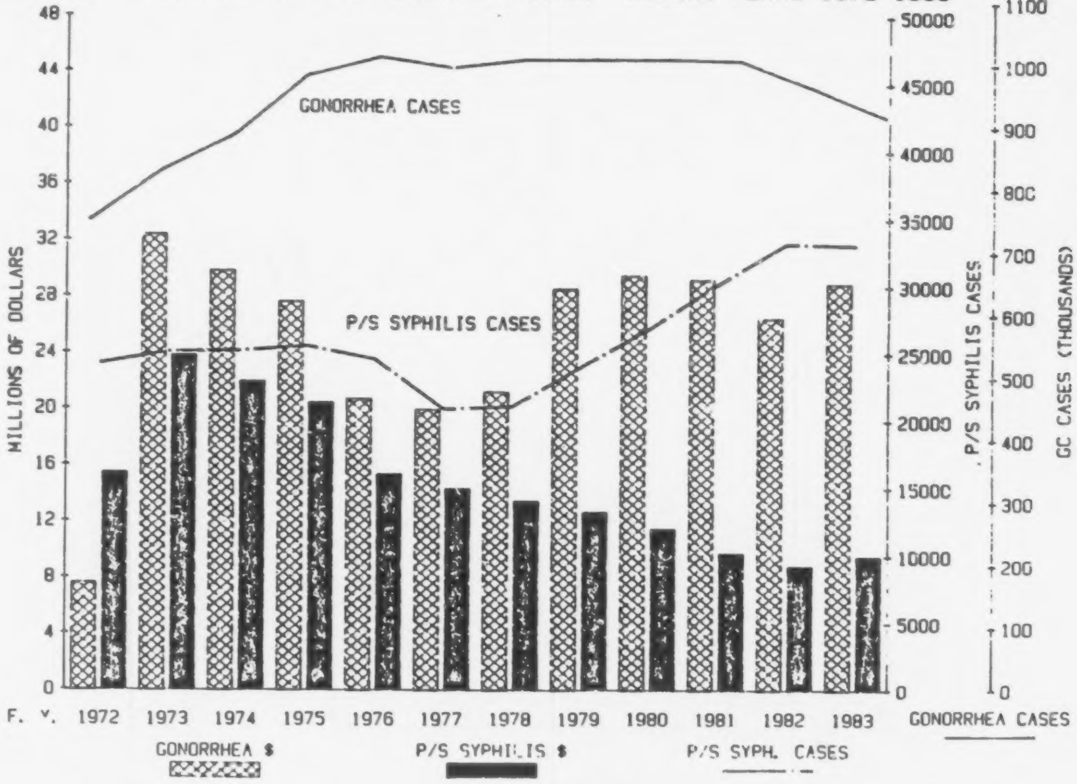
We applaud the Sexually Transmitted Disease control program for its initiation this year of an effort to improve clinical training in medical schools. We believe this is a critically important contribution to the control of these diseases. We urge this Committee to include strong report language expressing its support for this effort. We believe it should be a national goal that every medical school in this country institute sexually transmitted disease training programs through course curricula and liaison with public health programs.

Section 318(b) of the Public Health Service Act provides that five percent of all funds appropriated to the Sexually Transmitted Disease program be allocated to projects of information, education, demonstration and research. We are deeply concerned that other program priorities have drawn funds away from this effort, and that the purpose has not been fulfilled. (Reauthorization legislation introduced in the House would increase the amount required to at least 10% of appropriations.) Education and information are the first line of prevention for these diseases, and the only prevention for a disease like herpes. We believe that this component of the program must have a higher priority, and hope this Committee will urge the program to carry out the purpose of this legislation, especially in educating young people, training medical students, investigating innovative new ideas and methodologies, and developing a nationwide computerized system of data collection.

VD affects as many as one out of every 4 Americans between the ages of 15 and 55. The existing public health model was successful in combatting syphilis, but the epidemics of other diseases now are far too pervasive and over-whelming for that system, and we must look for new ways to reach greater numbers of people. This year there will be 600,000 new cases of herpes, one million cases of pelvic inflammatory disease which leads to sterility, 80,000 new cases of syphilis, 110,000 women pathologically sterilized, and more than 80,000 ectopic pregnancies.

The effort against AIDS is a critically important one, but it has drained resources and energies from the VD program, which should not continue. More than 30 million Americans suffer from venereal diseases. We urge you to provide substantial increases to the venereal disease prevention and control program. Thank you.

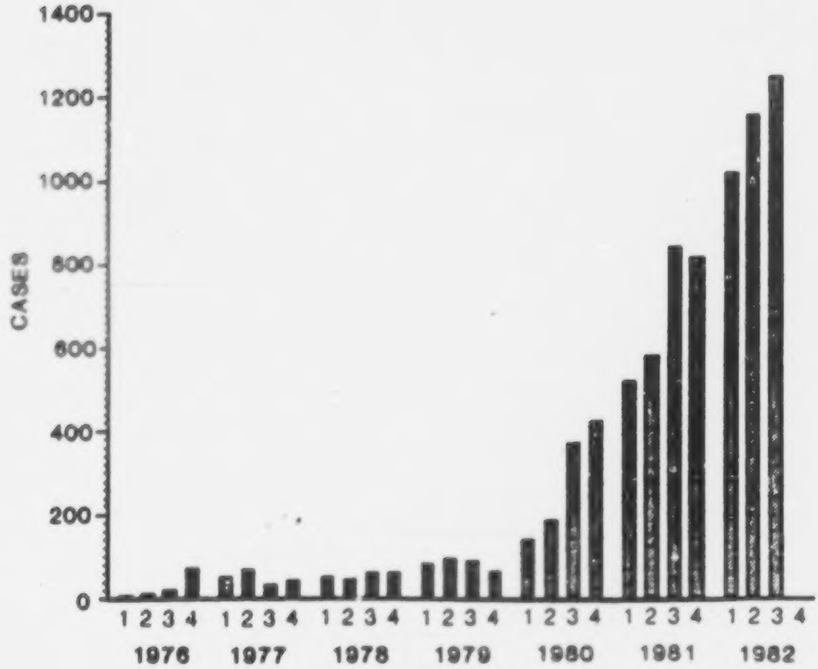
GONORRHEA AND PRIMARY AND SECONDARY SYPHILIS CASES VS. FEDERAL PROJECT GRANTS TO STATES IN 1983 DOLLARS* U.S.: FISCAL YEARS 1972-1983



*ADJUSTMENTS FOR 1983 $ BY PRICE DEFLATERS FOR FEDERAL GOVERNMENT PURCHASES OF GOODS & SERVICES.

PENICILLINASE-PRODUCING NEISSERA GONORRHOEAE

NUMBER OF CASES OCCURRING BY QUARTER
UNITED STATES (INCLUDING OUTLYING AREAS): 1976-1982



SUBCOMMITTEE RECESS

Senator WEICKER. The subcommittee will stand in recess until Thursday, April 12.

[Whereupon, at 12:03 p.m., Wednesday, April 11, the subcommittee was recessed, to reconvene at 9 a.m., Thursday, April 12.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1985

THURSDAY, APRIL 12, 1984

U.S. Senate,
Subcommittee of the Committee on Appropriations,
Washington, DC.

The subcommittee met at 9:05 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker, Proxmire, Burdick, and Inouye.

NONDEPARTMENTAL WITNESSES

OPENING STATEMENT

Senator Proxmire [presiding]. The subcommittee will come to order. Today we will hear public witnesses on the budgets of the National Cancer Institute, the National Heart, Lung, and Blood Institute, the National Institute of Child Health and Human Development, and the Health Resources and Services Administration.

To my right you will see three lights, and I suggest you begin to summarize your statement when you see the yellow light. You will have 4 minutes before the yellow light appears, and then 1 more minute to end your testimony.

All statements will be entered into the record in their entirety.

As you can see by today's schedule, we have a very full morning. We have a number of witnesses.

STATEMENT OF DR. BENJAMIN F. BYRD, PROFESSOR, CLINICAL SURGERY, VANDERBILT UNIVERSITY

PREPARED STATEMENT

Senator Proxmire. Our first witness is Dr. Benjamin Byrd, professor of clinical surgery, Vanderbilt University. We are very honored to have you, Dr. Byrd. Before you begin, we will insert your statement in the record.

Dr. Byrd. Thank you, Senator.

[The statement follows:]

STATEMENT OF DR. BENJAMIN F. BYRD

Mr. Chairman and members of the Committee, I am pleased to be here today to present the "citizen's cancer budget" on behalf of the American Cancer Society, the world's largest voluntary health agency with over two and one quarter million active volunteers.

My name is Benjamin Byrd. I am Professor of Clinical Surgery at Vanderbilt University and Chairman of the Surgical Advisory Board of St. Thomas' Hospital in Nashville, Tennessee. I was the National President of the American Cancer Society in 1975 and served as Chairman of its Public Issues Committee. I am proud to still serve on the National Board of Directors of the American Cancer Society and am a member as well of its Research Committee and its Public Issues Committee.

Mr. Chairman, when I first chose oncology as my specialty over 35 years ago, 75% of patients developing cancer died within five years. Today, a young doctor choosing that specialty knows that almost one of every two of his or her patients will live five years or longer. That is progress.

During my career, I have witnessed the almost total elimination of death from cervical cancer because of the pap smear. This is early detection. I have seen the survival rate for children with cancer jump from around 30% - only one in three children living for five years or more - to over 50%. I recently treated a young woman in her early 20's for Hodgkins Disease. Fifteen or twenty years ago, I would have had to tell her she was going to die. Today I can tell her that she has an almost 2 in 3 chance of cure. This is improved treatment. In my own particular specialty, breast cancer, there was a static survival rate for many years. There is now evidence of appreciable improvement.

Unfortunately, now that we are beginning to gain some control over the more traditional cancer killers of women, we are sadly confronted with a tremendous increase in lung cancer deaths among women. At least 12 states have now reported that lung cancer surpassed breast cancer as the number one cancer killer of women in those states. The next 24 months will see this true for the nation as a whole. In this current year alone, 135,000 people will die because of cigarette smoking. That means that one third of the people who will die from cancer in 1984 could have possibly avoided the pain and the tragedy of their death simply by not smoking.

The remarkable progress I have been privileged to be part of has not happened through serendipity. It has happened because of remarkable strides which have been made in treatment and early detection of cancer. It has come about through the dedicated efforts of the cancer research community and through the hard work of our clinical oncologists. They have been able to carry out that work in large part because of you and your colleagues who have gone before you. Bench research is essential but it must be translated into clinical practice.

Through the 1970's every Congress and every Administration recognized the importance of the struggle against this disease, recognized the devastation it was causing our citizens who had to live with it, and our federal establishment acted. Then, during the 1970's and 1980's, we saw an increasing preoccupation with other budgetary matters. Deficits were growing and programs had to be cut. Unfortunately, the NCI became one of the victims of those cuts and I believe that was a poor choice.

Last year this Committee determined that it was time to reverse that trend. I express today the gratitude of the members of the American Cancer Society. You clearly understood the simple economics of cancer. This year cancer will cost our economy almost $11 billion in medical expenditures and not less than $13 billion more in lost wages and forced liquidation of assets. Last year the cost of medical care during the final year of life for the average American who died of cancer was $22,000.

Of course, the human costs is of much greater interest to all of us. One in three of us in this room will get cancer. It will strike in more than three of every four American families. This year alone there will be 870,000 new cases and 450,000 Americans will die from cancer.

Obviously, the fight is not won. The national struggle against cancer begun by our government in 1972 and reestablished by the members of this Committee last year must be improved upon this year. I am here to ask for $1.5 billion for the National Cancer Institute in FY'85. Let me emphasize the fact that the American Cancer Society does not accept federal funds. Yet we understand the problems you face in determining where to allocate our ever-decreasing government resources. However, we firmly believe the health of the nation is not the place to economize. That is a false economy and the American people will not tolerate it.

While the Congress has been careful to make certain that basic biomedical research has continued at a respectable, although diminished, pace other cuts have begun to hamper that research and no amount of money put directly into research grants can possibly change that. Our cancer laboratories around the country are becoming hopelessly out of date. In a 1983 report called Strengthening the Government-University Partnership in Science, the conclusion reached was that deterioration and obsolescence of research equipment and facilities in our universities has begun to threaten the quality of our science and it placed the cost of solving the problem at between $1 and $4 billion.

I recently put forth a successful motion at the American Cancer Society Board of Directors meeting requesting that the ACS provide $75,000 to fund a study on the current status of our cancer research facilities around the country. That money will match the $75,000 Dr. Armand Hammer, Chairman of the President's Cancer Panel, has agreed to contribute to the cause. We have taken this step because the Department of Health and Human Services was unable to do so and because we were concerned. Over the last decade, we have substantially increased our scientific enterprise in the area of cancer research and these scientists need up-to-date laboratories in which to work.

In the one meaningful report which does exist entitled "Health Research Facilities: A Needs Assessment," which was presented to the President's Cancer Panel in 1983, Dr. Donald Fox reported that, based on questionnaires sent to 106 institutions receiving NCI support, "The 1980 construction needs totalled $221 million. Projected needs for 1981 - 1985 were estimated at $449 million, with $190 million to be sought from the NCI. Based upon the NCI program experience, this will be translated into a funding need of about $149 million over the 1980-1985 period, or approximately $20 million per year during that time."

We urge this Committee to fund construction for the National Cancer Institute at more than the $2 million level requested by the Administration in their budget. Clearly that request was based on real need and we know this Committee's record on meeting such needs and hope you will continue that excellent record in this case. I have attached a chart on the history of funding for construction through the National Cancer Institute.

Further, the Society feels very strongly that we must place a greater emphasis on the clinical trials program. Some of the work being done with the clinical trials funds includes much of the research being done on biologicals and biological response modifiers. These natural products may well be the cancer treatment of choice of the future. Monoclonal antibodies which can be designed specifically to target cancer cells promise to be effective for diagnosis and treatment either armed with radioisotopes or toxins or by themselves. In addition, drug development work is frequently done under the clinical trials program. Testing promising drugs to discover proper dosage, extent of toxicity and other vital information necessary to develop proper treatment modalities for a drug is among the most important work we are doing in cancer research. It is drugs that have caused the dramatic decrease in death from such former killers as testicular cancer which was once an almost certain death sentence and now has a better than 90% cure rate. These programs must be continued at full funding and I urge this Committee to fund these programs at the level recommended in the NCI By-Pass Budget.

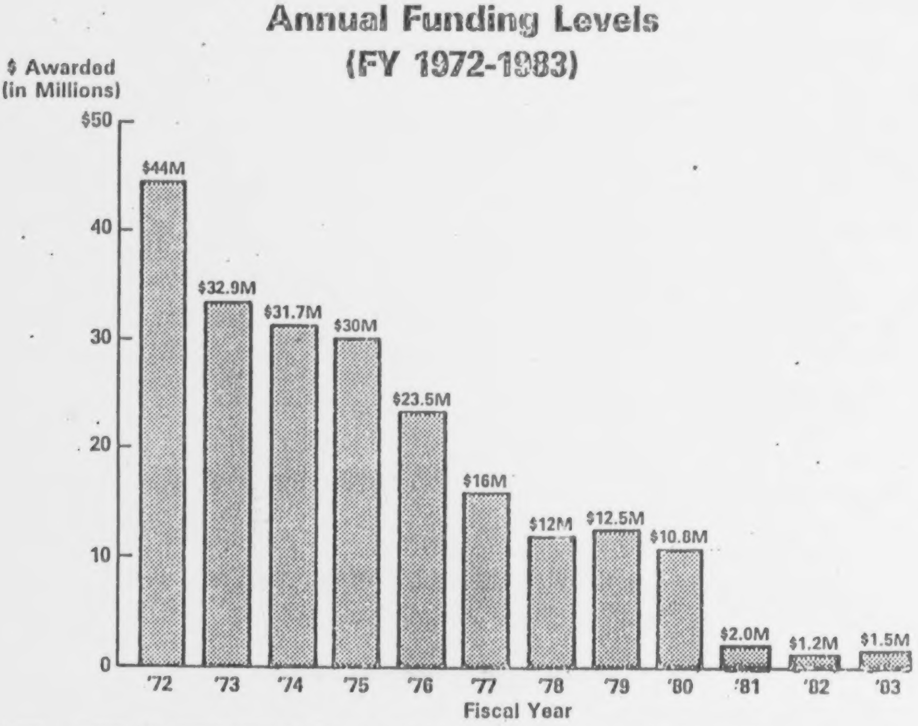
In addition, as a physician who treats patients, I know how important it is that we have the best available information on new treatment methods to our doctors in the shortest period of time. The work done by biomedical researchers in the laboratory is important but the laboratory is there to serve the patient and the work of the laboratory can only be proved out through clinical research, the research carried out so ably by our doctors and scientists in our Cancer Centers. A still current need is the money to complete the originally intended geographic pattern for the Centers and to further expand their work. Information available to the NCI shows that the Cancer Centers program improves treatment within a radius of 300 miles around each of our Centers because of improved physician awareness and training and offers of support services. All of this makes the Cancer Centers program of vital importance to our efforts.

The Cancer Control Program has improved significantly in recent years and much of the cancer prevention research on smoking cessation, on diet and fiber, on chemoprevention and in other areas is being done as part of that program. We need to focus on this exciting endeavor and increase funding for that program.

These are just some of the areas in which funds could be used beyond that envisioned by the Administration when they requested only $1.1 billion for the NCI. There are many, many more.

In addition, we feel the Committee should consider higher funding levels to ensure the award of at least 900 to 1,000 research grants. Basic biomedical research is, after all, the foundation upon which our cancer program rests. The Organ System Program should be fully funded and we must do all in our power to ensure that research and clinical career opportunities for talented young men and women are increased through our federal training programs rather than decreased as is now the case. We should also be fully funding the grants projects of the Cancer Centers. Gentlemen, I am only scratching the surface; the list could go on and on.

Cancer is the most feared disease in our nation. It is associated by our citizens with prolonged and painful death. Its incidence is so great that it is known to all of us personally either because it has struck us or has hit a family member or friend. Look to the person to your left and to your right, gentlemen. One of the three of you will get cancer. Please help make sure that whichever one of you it will be will live, and live happily and well after the experience.



NOTE: THESE ARE CONSTRUCTION FUNDING LEVELS FOR THE NATIONAL CANCER INSTITUTE.

Dr. BYRD. Senator Proxmire, members of the committee, I am here today to present the citizen's cancer budget on behalf of the American Cancer Society.

My name is Benjamin Byrd. I am clinical professor of surgery at Vanderbilt University in Nashville, TN, and I was national president of the American Cancer Society in 1975 and am a member of its public issues and research committees.

Mr. Chairman, when I first chose oncology as my specialty over 35 years ago, 75 percent of patients developing cancer died within 5 years. Today, a young doctor choosing that specialty knows that almost one of every two of his or her patients will live 5 years or longer, and that is progress.

Through research and education, we have made enormous strides in early detection, cancer prevention, and improved treatment.

The remarkable progress I have been privileged to be a part of has not come about through serendipity. It has occurred because of the dedicated efforts of the cancer research community and through the hard work of our clinical oncologists.

They have been able to carry out that work in large part because of you and your colleagues who have gone before you.

Through the 1970's, every administration and Congress joined—in fact, helped lead—the struggle against cancer.

Then in the late 1970's and 1980's, because of growing concern over budget deficits, we saw a disturbing change in the way the Federal Government viewed the cancer program. Budgetary economy was achieved in part at the expense of the health resources of our Nation.

Last year, this Congress began the reversal of such trends, and I wish to express the gratitude of the American Cancer Society for that. However, your work has just begun.

I am here to ask for $1.5 billion for the NCI for the coming year. This is money that could be well spent.

The American Cancer Society has joined with Dr. Armand Hammer to fund a study on construction needs, essentially the updating of laboratories for our researchers.

However, even without that study, we know that the $2 million requested by the administration is woefully inadequate. We need to increase substantially our commitment to the all-important Clinical Trials Program, which has been so helpful in drug development and in work with biologicals such as monoclonal antibodies.

We need to target the Cancer Control Program for increases in funding so necessary work on prevention issues can continue at an even greater pace.

We feel this committee should provide for no less than 900, and preferably 1,000, basic research grants; that the Organ System Program should be funded; that training programs which ensure research and clinical career opportunities for our talented young men and women are increased; and that the originally envisioned geographic pattern of our Cancer Centers Program is completed and the Cancer Center Grant Program is fully funded.

Gentlemen, I am only scratching the surface. The list could go on and on.

This year, 450,000 Americans will die from cancer. It will kill 72 of our citizens every minute.

Cancer is the most feared disease in our Nation. It is associated by our citizens with prolonged and painful death. Its incidence is so great that it is known to all of us personally, either because it has struck us or has hit a family member or friend.

Look to the person to your right and to your left, gentlemen. One of the three of you will get cancer. Please help make sure that whichever one of you it will be will live happily and well after the experience.

Senator, thank you.

Senator PROXMIRE. Thank you, Dr. Byrd, for an excellent statement, and I must say you make a very strong case for a very good cause.

You are asking for an increase of how much above the President's budget request?

Dr. BYRD. The bypass budget, I believe, is about $1.17 billion, and this would run $3.2 million above that, and it would be in the areas where I have enumerated the need for support, and that is in——

Senator PROXMIRE. $3.2 million above that?

Dr. BYRD. $320 million above that.

Senator PROXMIRE. $320 million?

Dr. BYRD. $320 million.

Senator PROXMIRE. $320 million?

Dr. BYRD. Right.

Senator PROXMIRE. The information that I have here is that your request would be about $398 million above the President's budget.

Dr. BYRD. It would be right at $400 million above that, yes.

Senator PROXMIRE. All right, very good.

Now, have any of the National Institutes of Health ever received an increase of this magnitude in percentage or actual dollar terms as far as you know?

Dr. BYRD. I am not sure that I can answer that question. The members of our staff here and the staff of the American Cancer Society assure me that this has not before been the experience of any of the other numbers of the National Institutes of Health.

Senator PROXMIRE. Is it reasonable, in your view, to expect the Cancer Institute to be able to integrate an increase of this dimension into their budget and do it efficiently?

Dr. BYRD. Without any particular new areas of concern for the National Cancer Institute, but simply with an implementation of the programs which are ongoing and with the modernization of research facilities, I think that all of the requested funds could be gainfully employed.

Senator PROXMIRE. As you can see, we are pressed for time.

Dr. BYRD. Right.

Senator PROXMIRE. If you would like to submit any documentation of that for the record, it would be very helpful to us. We are all very sympathetic. Senator Weicker, chairman of the subcommittee, is particularly sympathetic, and we will do all we possibly can, but I think your case would be stronger if you could show how these additional funds could be spent quickly and efficiently.

Dr. BYRD. I will see that that is done. Thank you very much, Senator.

Senator PROXMIRE. Thank you, Dr. Byrd, very much.

STATEMENT OF JOHN R. DURANT, M.D., MEMBER, PUBLIC ISSUES COMMITTEE, AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Senator PROXMIRE. Our next witness is Dr. John Durant, member of the public issues committee, American Society of Clinical Oncology.

Mr. Durant.

Mr. DURANT. Thank you, Senator, Mr. Chairman, very much.

I am Dr. John Durant. I am the president of the Fox Chase Cancer Center in Philadelphia. In not too long you will hear from my predecessor, representing another organization.

I am certified by the American Board of Internal Medicine, and I am the chairman of its subboard of medical oncology.

I was the founding director of the University of Alabama's Comprehensive Cancer Center and the Lurleen Wallace Cancer Research Institute.

I am the former chairman of a national group of clinical investigators performing clinical trials of new treatments and potential cures for the principal cancers of adults.

Today, I am representing the American Society of Clinical Oncology as a member of its public issues committee.

I would also like to think I am representing my wife, who this month celebrates her fourth year free of breast cancer, and my sister who is under successful treatment for chronic myelogenous leukemia.

The American Society of Clinical Oncology was founded 20 years ago and has now become the Nation's largest organization of specialists involved in cancer patient care. We conduct the majority of clinical cancer research and training of clinical cancer specialists.

We believe the National Cancer Program has made enormous strides. We would like to remind you that since it began over 12 years ago the mortality from cancer has fallen from 4 in 10 now to 1 in 2. We believe the goals stated by Dr. DeVita of reducing that to one in four by the end of the century are feasible.

We are concerned, however, that the promise of the future will not be realized unless there is adequate support for the National Cancer Program. Every advance in basic science knowledge that might benefit cancer patients must be applied in clinical trials performed by trained physicians, or the potential benefit to mankind of this new scientific knowledge will not be realized.

We are concerned at the present time because the allocation of funds to support basic research is not enough, but we are more concerned because the allocation of funds to support the National Cancer Institute's program of clinical trials, which are conducted by national cooperative groups and by cancer centers, have not kept pace with inflation.

We would like to remind you that the Congress suggested that the RO–1's and the PO–1's be funded at full recommended levels but that the National Cancer Institute has not applied that instruction to those grant mechanisms supporting both the cancer centers and the clinical cooperative groups.

The clinical cooperative groups are currently funded at 80 percent of currently recommended levels, and the cancer centers are funded at 15 percent less than the recommended levels.

We urge, therefore, that in consideration of the needs of the program and the past achievements and great benefits which are now at hand and which have been realized from this program, that the committee recommend the appropriation from our standpoint of $1,300,000,000 for the National Cancer Institute for the fiscal year of 1985.

We urge that you express your intent to the National Cancer Institute that it support clinical research, including that conducted by cooperative groups and cancer centers, by funding those grants at recommended levels in the same manner as applied currently to RO–1 and PO–1 grants.

We estimate that this would require approximately $20 million of new funds.

We urge that the committee call for a study by the National Institutes of Health of the patterns of funding of clinical research in all the institutes since the fiscal year of 1980. This study should focus on clinical research by physicians employing human subjects in clinical trials funded by each type of award employed since 1980 by each institute, including intramural research. The number of awards in dollars allocated should be shown for each type of funding mechanism by year.

We recommend that the committee request the report be delivered to it by January 1985, prior to the appropriations hearings upcoming next year.

Such a study will enable the committee, the OMB, and the NIH to accurately ascertain the impact of policy decisions on the funding of clinical research by all mechanisms.

Fourth, we recommend that the stipend levels for NIH pre- and postdoctoral trainees be increased to levels equaling those in other Federal agencies and in teaching hospitals. The estimated cost of such an increase, without decreasing the number of trainees, would be approximately $33 million.

Thank you very much for your attention.

[The statement follows:]

STATEMENT OF DR. JOHN R. DURANT

Mr. Chairman, I am Dr. John Durant, President of The Fox Chase Cancer Center in Philadelphia. I am certified by the American Board of Internal Medicine and its Sub-board of Medical Oncology. I was the founding director of the University of Alabama Comprehensive Cancer Center and the Lurline Wallace Cancer Research Institute. I am a former chairman of a national group of clinical investigators performing clinical trials of new treatments and potential cures for the principal cancers of adults. Today, I am representing The American Society of Clinical Oncology (ASCO) as a member of its Public Issues Committee.

THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology was founded 20 years ago and has become the nation's largest organization of specialists involved in providing cancer patient care, conducting clinical cancer research, and training cancer physician specialists. Members of this Society are involved directly, or as consultants, in the care of the majority of the cancer patients in the United States. Its members include the nation's leading physicians in medical oncology, pediatric oncology, radiation oncology, surgical oncology, gynecologic oncology and also basic scientists in pathology, immunology, pharmacology, biostatistics and other areas of basic biomedical science. Collectively, this Society represents the nation's major resource of specialists in the diagnosis and treatment of cancer patients, the application of research to cancer patients and the training of the cancer physicians and clinical researchers of the future. Approximately half of its members are practicing physicians caring for the nation's cancer patients in their offices and in many community hospitals, and half are engaged in research and training in literally all of the nation's schools of medicine, cancer hospitals, centers and institutes.

THE NATIONAL CANCER PROGRAM

The National Cancer Institute has developed the most effective national program of cancer research and control in history. It involves every major university, medical school, and cancer center, and the majority of the teaching hospitals in the United States, in a search for the cause, prevention, and cure of human cancers. The nation's universities and medical centers have responded by making substantial commitments of their precious resources of personnel, space and development funds to the national cancer program. They have matched federal awards for cancer research, training and construction of laboratories, research beds and clinics, dollar for dollar.

During the past 10 years, the National Cancer Program has attracted many basic scientists to direct their talents to problems in cancer biology and they are now uncovering the causes and methods of preventing this disease. Also, many of the country's brightest young physicians have been recruited into training programs and careers in clinical oncology and research. The several years which have been required to develop and train new physicians and basic scientists in cancer-related fields, to renovate and construct laboratories, research beds and clinics and to conduct clinical trials of new treatments, have been wisely and effectively invested. The most remarkable national medical research program yet known is now in place and functioning. And, most important, the National Cancer Program has already begun to realize its objectives.

EXAMPLES OF REDUCED CANCER MORTALITY

Since initiation of the National Cancer Program, the national cancer mortality rate has decreased for all Americans under the age of 45. Half of all patients with the most serious forms of cancer now survive their disease five years or more and many of them are cured.

- Acute lymphoblastic leukemia, the most common form of cancer among children, formerly 100% fatal, now can be cured in approximately half of such cases.
- 90% of women with early cervical cancers can be cured.
- The survival of women with breast cancer has increased from 63% in 1960 to 72%.
- The survival of patients with a highly fatal form of bone cancer, osteogenic sarcoma, has risen from 26% in 1970, to 41%.
- The national mortality rate for ovarian cancer has decreased by 38%.
- The mortality of premenopausal women with breast cancer has decreased by 15%.
- Deaths due to testicular cancer have declined by 43%.
- Mortality due to Hodgkins disease has declined by 56%.
- Clinical trials have demonstrated improved survival for patients with advanced stomach cancer, and the first evidence that combination chemotherapy following surgery improves survival in patients with stomach cancer.

THE IMPORTANCE OF CLINICAL INVESTIGATIONS

Almost, without exception, the major advances in the treatment and cure of human cancers have resulted from carefully designed clinical trials. The majority of controlled clinical trials are conducted by physician-investigators of the nation's cooperative groups and cancer centers. Clinical oncologists, trained in the design, conduct and evaluation of clinical trials, constitute the nation's expertise in the application to cancer patients of the advances in laboratory research that may lead to the prevention, detection, treatment and cure of more human cancers.

In the hospitals which lead the nation's clinical cancer research, the management of a cancer patient is increasingly the responsibility of teams of physicians representing all specialties necessary for complete diagnosis, treatment and rehabilitation. These include medical and pediatric oncologists, surgeons in many specialties, radiation oncologists and gynecologic oncologists. Now, we are challenged more than ever before to bring basic science advances to cancer patients. Every advance in basic science knowledge that might benefit cancer patients must be applied in clinical trials performed by trained physicians or the potential benefit to humankind of the new scientific knowledge will not be realized.

The hallmark of the 1980's will be even closer collaboration among basic and clinical scientists in order to exploit the potential advantages to cancer patients brought by the discovery of monoclonal antibodies, oncogenes, recombinant DNA technology, new chemical and biological agents, and the discovery of compounds capable of preventing or reversing the effect of carcinogens. The ultimate test of how these recent breakthroughs in basic science can benefit humankind will be in the clinic and at the bedside. Research on the application of these new technologies must be done by teams of physician investigators trained in the demands of sophisticated clinical investigations and working in closer link with basic science colleagues. The virtual explosion in molecular biology of the last three to five years offers much promise in understanding the nature of the cancer cell and opens many new leads which demand clinical studies. However, at this time of great opportunity, we find ourselves with a shortage of dollars to fund clinical research.

The cooperative clinical investigation groups and cancer centers have committed themselves to a new national program by which their sophisticated treatment protocols can be available to the nation's cancer patients under the care of practicing clinical oncologists at community hospitals through their affiliation with trained clinical investigators. The Community Clinical Oncology Program (CCOP) was planned by the NCI to accomplish this. The NCI's Physician Data Query (PDQ) computer network was designed to give information to practicing physicians about the best treatments available for their cancer patients. Both programs depend for their success upon the clinical research of the cooperative groups and cancer center.

CANCER: THE NATION'S PRIMARY HEALTH CONCERN

The widespread fear of cancer among the citizens of our nation is justified. The image of a prolonged, debilitating, disfiguring and painful death is all too often true. The nation applauded the priority given to the conquest of cancer by the National Cancer Act of 1971. In carrying out the mandates of that Act and its revisions, the National Cancer Institute has developed a program which involves the vast majority of the nation's physicians who are trained in clinical oncology as well as the nation's researchers and cancer educators in both clinical and basic science. Moreover, that national plan is beginning to show dramatic payoffs for the American people. The payoffs are measured at the clinical level by reduced national mortality due to cancer and at the laboratory level by the dramatic discoveries of recent years which now must be subjected to clinical trials. However, the apparatus for putting these remarkable advances to use in preventing cancer, in detecting persons at high risk of developing cancer, in more effective treatments and increasing cures, is in danger due to insufficient funding.

BUDGET FOR THE NATIONAL CANCER PROGRAM

Mr. Chairman, The American Society of Clinical Oncology believes that this is a time of great opportunity in the National Cancer Program. This could be the most exciting decade ever in the history of cancer research and a time when we can realize important clinical applications and major human benefits. We have this opportunity today because of the National Cancer Act of 1971 and its amendments. But we fear that we are in imminent danger of losing the opportunity for important gains. We have noted with increasing concern that the budget of the National Cancer Institute has increased less than 3% per annum since 1980. The National Cancer Institute funded 760 grants in 1983 but was unable to fund 1,870 approved applications which were recommended for funding by groups of peer scientists. We are concerned because the allocation of funds to support the NCI program of clinical trials by national cooperative groups and cancer centers has not kept pace with inflation. These are the programs most urgently needed to apply important laboratory discoveries to the nation's cancer patients and citizens at high risk of developing cancer. These are the programs to which physicians in community practice are being referred by the NCI's PDQ system. These are the programs which are to provide state-of-the-art protocols and research expertise to hospitals participating in the Community Clinical Oncology Program (CCOP). These are the programs which will be depended upon for clinical trials of cancer prevention, the reversal of carcinogenesis in high risk persons and for teamwork involving surgeons, radiation therapists, chemotherapists and immunotherapists. The NCI budget for clinical trials of new treatments urgently needs more funds for clinical cooperative groups, cancer center support grants, and clinical program projects in order to regain momentum.

While the first decade of the National Cancer Act was a period of building human and physical resources and developing a national program of cancer research, the 1980's are forecast as a decade of application to our cancer patients and to citizens at risk of cancer of the remarkable scientific advances the National Cancer Program has already produced. We now know how to prevent over half of human cancers. The apparatus is in place. However, we are suffering a loss of momentum and a loss of career cancer scientists.

Funding stability is required for organizations such as cooperative groups and for cancer centers which design and conduct clinical trials often requiring two years to enter a sufficient number of patients onto the study and up to five years of patient follow-up to obtain statistically valid answers to the multiple scientific questions the trial was designed to answer. Funding stability is needed to attract and train outstanding young physicians in clinical specialties to careers in the demanding science of clinical investigation. The stipends for NIH pre and post-doctoral trainees in research should be increased to parity with other federal agencies and teaching hospitals.

IMBALANCE IN RESEARCH FUNDING

Mr. Chairman, we endorse the priority which the OMB and the Congress have given to funding investigator-initiated research grants, but we believe that present constraints on the NCI budget have led to an increasing imbalance and instability in the funds available to sustain the nation's clinical research by cooperative groups, cancer centers and other clinical investigators. The OMB has directed the National Institutes of Health to fund 5,000 investigator-initiated research grants and the Congress has directed that they be funded in full at recommended levels. In carrying out these mandates, the NIH determined that the policy should apply to type R01 and P01 grants.

The NCI supports very little clinical research by the R01 grant mechanism and only a modest proportion of P01 grants include clinical research components. The NCI may be unique among the institutes in thus exempting a major portion of its clinical research from full funding since the NCI now employs cooperative agreements to fund the majority of its clinical trials. Apparently, other institutes include a large proportion of clinical investigations in their R01 and P01 grants and thus allow peer review and scientific merit to select for funding the best of both basic and clinical research.

The proportion of the NCI budget devoted to cooperative clinical investigations has declined each year since 1980 and is projected to decline further in fiscal years 1984 and 1985. Cooperative groups constitute the single largest interface of the National Cancer Program with the American people. They provide an effective means of improving the quality of care of cancer patients in community institutions as well as in academic research centers. However, competing renewal grants for cooperative groups are currently being funded at 20% less than recommended level and cancer center core grants at 15% less than recommended. The projected funding for cancer center core support grants in FY 1985 is $1,000,000 less than the current level of support, although the same number of cancer center support grants are projected.

RECOMMENDATIONS

1. We urge, that in consideration of the past achievements and the great benefits which now can be realized from the National Cancer Program, that the Committee recommend the appropriation of $1,300,000,000 for the National Cancer Institute for fiscal year 1985, including the appropriations for research training in clinical oncology and the cancer control program.

2. We urge that the Committee express its intent that NCI-supported clinical research, including that conducted by cooperative groups and cancer centers, be funded at recommended levels in the same manner as applied to R01 and P01 grants. This will require approximately $20,000,000 of new funds.

3. We urge the Committee to call for a study by the National Institutes of Health of the patterns of funding of clinical research in all institutes since FY 1980. The study should focus on clinical research by physicians employing human subjects in clinical trials funded by each type of award employed since 1980 by each institute, including intramural research. The number of awards and the dollars allocated should be shown for each type of funding mechanism by year.

   We recommend that the Committee request the report be delivered to the Committee in January 1985, prior to the appropriations hearings upcoming next year. Such a study will enable the Committee, the OMB and the NIH to accurately ascertain the impact of policy decisions on the funding of clinical research by all mechanisms.

4. We also recommend that the stipend levels for NIH predoctoral and postdoctoral trainees be increased to levels equaling those in other federal agencies and in teaching hospitals. The estimated cost for such an increase, without decreasing the number of trainees, would be approximately $33,000,000.

Mr. Chairman, thank you for this opportunity to express our views.

Senator PROXMIRE. Thank you very much, Dr. Durant, and these are very constructive and positive suggestions. We appreciate that very much.

You are calling for an increase of about 20 percent?

Mr. DURANT. Yes; if I may respond to the last——

Senator PROXMIRE. Over the current budget?

Mr. DURANT. Yes; question somewhat?

If you just look at the RO–1's and PO–1's, they are being funded down to only about 25 to 30 percent of the approved grants. So there's lots of good research approved and unfunded in the mill.

In addition, merely restoring the cuts that have been administratively made in the cooperative groups and the cancer centers would merely mean putting money back in that has already been recommended for expenditure, and if you add that to new ideas and the need for equipment and construction that has been identified by Dr. Hammer and the American Cancer Society, I think you will easily make it to $200 million.

Senator PROXMIRE. Thank you, sir. Thank you very much.

STATEMENT OF DR. ROBERT BRADFORD, FOUNDER, THE COMMITTEE FOR FREEDOM OF CHOICE IN MEDICINE, INC.

PREPARED STATEMENT

Senator PROXMIRE. Our next witness is Dr. Robert Bradford, founder of the Committee for Freedom of Choice in Medicine.

We are happy to have you, Dr. Bradford. Your statement will be inserted in the record at this point.

[The statement follows:]

STATEMENT OF DR. ROBERT W. BRADFORD

My name is Robert W. Bradford. I am president of the Bradford Research Institute, American Biologics and the Committee for Freedom of Choice in Medicine, Inc. I also am administrator of the American Biologics-Mexico, S.A. Research Hospital and Medical Center in Tijuana, B.C., Mexico.

I very much appreciate the opportunity to appear before this Subcommittee.

This nation continues to face an epidemic of cancer, one without parallel in modern history. And, despite semantical and statistical juggling by the authorities and experts entrusted with implementing cancer therapy, the reality is that more Americans are getting cancer than ever before and dying of it at ever-younger ages than ever before.

Including skin and cervical cancer, the conservative projection for 1984 is at least 1.2 million new cases of cancer to be diagnosed. Even if we accept the somewhat faulty database on which the National Cancer Institute statistics are based, we are looking at some 450,000 fatalities this year and such unsettling facts as cancer affecting about 1 out of every 3 people, killing 1 out of every 6, striking 2 out of 3 families and constituting the major killer of children under 14 and middle-aged women.

Many Americans, not only those of us in the so-called alternative health movement, are extremely dubious of the annual statements by the National Cancer Institute and American Cancer Society as to successes in the so-called Conquest of Cancer Program in terms of increases in five-year survival rates -- the so-called "cures" that cancer experts point to to claim success in the standard or orthodox approach to this condition. Of course, five years free of symptoms is not a cure, and increasing numbers of Americans develop alleged secondary cancers in the sixth, tenth or even fourteenth years following their alleged "cures."

Daniel S. Greenberg, editor/publisher of Science and Government Report, has been preeminent in the U.S.A. in monitoring the annual statistics put forth by the NCI, ACS and their allies as to cancer therapy success rates. He has recently noted that the NCI's 1983 year end report, suggesting a 48% five-year survival rate across the board, is misleading because the government's "reassuring numbers mask an ever rising death toll from cancer, as well as serious doubts among some orthodox and respected scientists concerning the efficacy of the federal government's $1 billion-a-year anticancer program."

Greenberg has noted that national cancer figures are derived from a sampling that covers 10 percent of the population. I might add that those same figures are rife with contradictions.

Such orthodox researchers as Dr. John Cairns of the Harvard School of Public Health -- and, for many years until his death, the late Dr. Hardin Jones, physiologist with the University of California -- have indicated that even some downturns in certain forms of cancer have nothing to do with treatments for those forms. The American Cancer Society, a profit-making private organization which largely determines what Americans know about cancer and which is responsible for enormous amounts of cancer research in this country primarily funneled into the orthodox or standard approaches which up to now simply haven't worked, and government agencies, lay great stress on early detection of cancer. This stress on early diagnosis likewise calls into question any actual advances in therapy. All sides will submit that, at least in dealing with gross symptoms, tnere is much greater life-extension possible following earlier rather than later diagnosis. This says nothing about treatments per se.

It is most interesting, in the meantime, to note the seemingly overnight discovery by the NCI, the ACS and, now, the entire Health and Human Services Department, that dietary elements may be linked to cancer and dietary elements may help prevent cancer. Utilizing the aphorism that that which prevents also cures, it is no longer a leap of faith for many orthodox or standard researchers to assume that dietary elements may actually be used to treat the disease.

Earlier this year, the NCI and ACS suggested "dietary guidelines" to help prevent cancer. These guidelines include the ingestion of less animal protein, more fiber, more fruits and vegetables and the consumption of foods containing Vitamins A and C, together with those fruits and vegetables suspected of having some undefined non-nutritive food factors in them, including cabbage, brussels sprouts and various members of the Cruciferae and Brassica families. I should like to point out that the NCI's own federally funded study on diet, nutrition and cancer, published in 1982, is a treasure trove of such information, including evidence of cancer prevention with selenium and a range of so-called non-nutritive food factors and related elements -- including so-called aromatic isothiocyanates whose best description in lay terms would be "laetrile."

All of this is all the more ironic since the moderately anti-cancer diet now championed by the NCI and ACS just happens to be what the majority of metabolic/

nutritional physicians have been suggesting over the past several decades. Within just the past five years, spokesmen for standard medicine in this country branded just such diets "bizarre" and "barbaric" when utilized as part of the therapies of such celebrated child cancer cases as Joey Hofbauer and Chad Green.

It is not only ironic but immoral that even as what one might term the American Medical Establishment now grudgingly concedes that diet may be involved in at least 50 percent of all cancer and is co-opting the dietary approaches to this disease long championed by physicians and scientists the Establishment long has branded as quacks, crooks and charlatans, we find that very Establishment still ruthlessly and viciously suppressing the medical pioneers who are creating the medical future.

These medical pioneers, involved in what has variously been termed holistic, biological, metabolic, nutritional, or orthomolecular medicine, continue to be harassed, persecuted, prosecuted and intimidated by a formidable combination of bureaucratic, state and monopoly medical power. This combination of powers and vested interests is in the de facto control of medical practice in this country and is violently opposed to any practice, theory, device, modality or approach which has developed outside its confines. The various elements on the "hit list" of this combination have and do include simply in recent times laetrile, DMSO, Vitamin B15, EDTA chelation therapy, chiropractic, herbal remedies, colonics, megavitamin therapy, and the like. Because of this, the Committee for Freedom of Choice in Medicine is shortly filing a complaint with the United Nations Committee on Human Rights against the U.S. medical establishment.

Simply in the matter of cancer, there is a lengthy history of vigorous and vicious suppression of modalities which have been demonstrably useful in cancer but which were developed outside the pale of orthodoxy or were unsusceptible to patent control or both. These remedies, to name only the more prominent, have included the Koch agents (Glyoxilide and others), the Hoxsey herbals, the Ferguson herbal compounds, Krebiozen, Coley's toxins (recently removed from the "unprovens" list), laetrile, ADS tea, Tumorex and other amino-acid combinations. Proponents and users of these and other substances have been arrested, investigated, set up, bought off, or otherwise isolated, neutralized and, when possible, eliminated from the medical marketplace, all to the detriment of American health.

Having devoted more than a decade of my professional life to dealing with the development of new approaches to degenerative diseases in general and cancer in particular, and after having dealt with literally thousands of doctors, researchers and patients during the course of my involvement with major clinics and hospitals which administer what is generally known as metabolic or nutritional therapy, I can only be appalled and chagrined as a taxpayer and an American citizen at the misdirection of cancer research funds in this country.

The cancer incidence and survival statistics are eloquent testimonies to the failure of the tried-and-untrue approaches to cancer which have so enriched the coffers of the $35-billion-a-year cancer industry: surgery, chemotherapy and radiation. This is not to say that these modalities have utterly no place in cancer therapy. But it is to say that reliance on them and them alone not only has done nothing to curb cancer incidence in this country, but, by any fair assessment, has worsened the problem.

There is an increasing interest in the Establishment, intriguingly enough, in immunotherapy -- harnessing the body's natural defenses to fight cancer. This is well and good, a step in the right direction. I would argue that immunotherapy is actually what the metabolic/nutritional doctors have been practicing for decades. The treating of cancer through holistic methods, including a vast array of natural substances, immune-stimulating elements, vitamins, minerals, enzymes, amino acids, vaccines and biologicals, represents a legitimate approach to cancer therapy which is developing, and in other countries has developed, a record of achievement and performance, particularly within an individualized, integrated program that does not exclude standard modalities. There are many approaches, ranging from one-shot or "magic bullet" substances and special diets to a completely eclectic program which includes many such modalities together with the conservative use of standard or orthodox modalities.

Virtually each of these individual approaches has considerable successes, some purely anecdotal, in its defense. There is far too great an abundance of credible positive effects against cancer occurring in credible people, and administered by credible practitioners, all operating outside the realm of what is usually considered orthodox oncology in this country, to be bereft of at least a considerable level of circumstantial evidence.

As administrator of the major intensive-care hospital in North America which uses a total, individualized, integrated program, I can attest to the successes and benefits of a truly eclectic program of cancer management in which the fullest possible range of so-called alternative therapies is administered in a 24-hour clinical setting by licensed and competent medical personnel. This is the American Biologics-Mexico, S.A. Research Hospital and Medical Center in Tijuana, B.C., Mexico, which has been implementing total treatment protocols for degenerative disease for more than three years. We are currently computerizing about 500 cancer patients, most of them Americans, who have been through the AB-Mexico programs. Making a very long story very short, we are seeing about 80 percent positive responses in cancer patients, a figure all the more impressive since most of the patients we are seeing there have been regarded as "terminal" and beyond hope or cure from so-called orthodox modalities.

Space does not permit my elaborating on the many treatments and cases which we have developed at AB-Mexico, though I certainly invite the most rigorous scrutiny of our approach by the competent American bureaus, administrations and departments, for we have nothing to hide. Our patients are living proof and speak for themselves. I also hasten to point out that we do not offer magical cures, or even cures per se at all. "Positive responses" include everything from simply feeling better to such dramatic effects as tumor destruction. I would be derelict if I failed to point out that even with a total program, terminal cancer remains a stubborn and frustrating foe and that we eventually lose many of our patients. For even these, however, the difference in our approach as compared to that of allopathic treatment-only in the U.S.A. is that the quality of life, let alone life extension, improves under what we generally call metabolic/nutritional therapy.

It is true that the various metabolic/nutritional clinics and clinicians in the U.S.A. have no tax-supported research database for adequate patient monitoring and followup. However, by analyzing the random information that can be gleaned from metabolic/nutritional clinics in the U.S.A. and outside the U.S.A., it is clear that the five-year survival rate in terminal cancer is about twice as good with these so-called alternative therapies as it is for standard or orthodox therapy based on chemotherapy, radiation and surgery.

In this country, the so-called alternative approaches have routinely been denied access to publication in professional journals, their proponents and advocates have been ridiculed, their practitioners frequently arrested, prosecuted and persecuted. At the level of federal financing for the Conquest of Cancer program, and at the level of private funding through the American Cancer Society, virutally no metabolic/nutritional therapies have even been seriously looked at, let alone funded.

I come before you today as an individual long involved with the cancer miasma. I am here to say that continued funding of, and reliance on, surgery, radiation and chemotherapy as the only acceptable treatments in cancer is a blind alley, a rat hole down which many billions of dollars, both public and private, have long been wastefully poured. If the federal government is to continue funding the National Cancer Institute, and if this body, which allegedly exists in the public interest, is to channel federal funds into worthwhile areas, I strongly urge and recommend that funding be considered in these areas:

1. Research, development and implementation of the Early Warning and Prophylaxis Systems (EWAPS) concept -- that is, the use of monitoring and diagnostic tests and methods which detect the subtle biochemical shifts and changes which, properly recognized and addressed, can head off not only cancer but degenerative disease in general. I suggest that this approach is the real, long-term answer to the degenerative disease calamity in this country. In terms of cancer, this might well mean a National Pre-Cancer Screening Test, availing itself of technology which exists now to head off potential cancer before it ever reaches the clinical stage.

2. Implementation of mixed therapies now. That is, the government should be looking at and researching every aspect of metabolic/nutritional therapies now. I would suggest a pilot program with selected patients and selected cancers to study (a) the effects of metabolic/nutritional therapy alone on selected patients and cancers, (b) the effects of standard therapies alone on a matching group of patients and cancers, and (c) the effects of combining both these approaches on another matching group. I add that the good offices of the Bradford Research Institute and American Biologics-Mexico, S.A., are available to help structure either (1) or (2).

3. Funding now for the B.R.I. to carry out within the United States a program of either (1) or (2) or both.

Whether (1), (2) or (3) can be done or not, I add my voice to the many clamoring for reform with the National Cancer Institute as well as the National Institutes of Health in the allocation of funds, to move away from drug-reliant therapy as the exclusively favored school of medicine in this country. If NCI is not prepared to fund or properly investigate and evaluate metabolic/nutritional approaches within a total, eclectic cancer program, I suggest it not be funded at all.

Dr. **Bradford**. I am Dr. Robert Bradford. I am president of the Committee for Freedom of Choice in Medicine. I am president of American Biologics, and I am administrator of the American Biologics Research Hospital in Tijuana, BC, Mexico.

The Bradford Research Institute has offices in five different countries. We are aware of alternative therapies that are being implemented throughout the world. We are implementing a number of those in Mexico.

First of all, as an overview, there are more people dying of cancer today at an earlier age than ever in the history of the United States. The World Health Organization has decreed that Western medicine, as we know it today, is not meeting the needs of the society. We fully concur with that resolution of the World Health Organization.

Without belaboring the failure of the war on cancer, let me get directly to where I think we should be spending money on the war on cancer, and let me give you an analogy if I may be permitted to do so.

We have a flood of cancer patients, and we are trying to sandbag the river, and we are losing that battle. Where we need to put our effort is up at the headwaters. We have got to start controlling this flood, and there isn't—and we can do that, and we are doing it with existing technology.

We are talking about what we call an EWAPS Program, an early warning and prophylactic system.

What we need is the ability to detect cancer subclinically. There are many flags that have been developed in the last year, in the last couple of years, where we are able to look at blood and urine profiles and we are able to see flags, where various polypeptides and various changes in body chemistry are detectable, that is, the thiocyanate level. Thiocyanate shifts in the blood occur as much as 1 to 2 years before the onset of a clinical case of cancer.

The EWAPS Program is where a good deal of the funds for national cancer research should be put. We need to concentrate on prevention as well as treatment, and that is well within the realm of technology as we know it today. There is a good deal, and that is not to say that we know all there is to be known about early detection, but certainly there is a tremendous amount that could be done.

We have treated over 500 cancer patients in our facility in the last 18 months. We get the failures from the American Medical Association in Mexico. We are running about 80 percent survival on those patients, and let me say that many of those patients come down in hospital—they are being flown down in hospital airplanes.

Basically, you need to—I want to go now into the treatment phase—what you need to do and what we need to pursue aggressively is the alternative methods in the treatment of cancer, and I do not mean the alternative methods exclusively. I mean integrating those methods with traditional methods.

We do surgery, we do lomthectomies. We do not get metastases. We don't get metastases because we do a very heavy systemic program before surgery. We back that up with a very heavy oxidative, systemic program. After therapy we are not getting metastases.

The surgery in this country could be greatly increased, the efficacy could be realized simply by integrating these alternative programs.

We are talking about now the National Academy of Science that published "Diet, Nutrition, and Cancer" last year, 1983, and we are talking about NNFA, nonnutritional food factors, and what are they talking about? Let's just take a look at a couple of them.

First of all, we are talking about benzyl aromatic isothiocyanates. Well, what is that? That is a fancy name for laetrile. All right.

And just one more point on that: Rutgers University published in Science in 1983—the most powerful free radical hydroxyl scavenger known to man is emiglin, injectable emiglin that can be given at very high doses. That is another word for laetrile.

We are talking about retinoic acids in vitamin A and in vitamin C. You are talking about a whole host of herbals and biologicals. We are talking about many therapies that are not approved in the United States, though they are used in Europe, such as hypothermia, for instance, such as magnetic therapy, for instance.

So what we really need to do is we need to not study these, Senator, because they have been studied. What you have is a political barrier that prevents the research and development that we are certainly most effective at doing, at being implemented into private practice. We are arresting physicians throughout the country today for using nutritional supplements, where at the research level we are developing those very nutritional supplements.

So in summary, we need to be seriously looking at alternative therapies. We are looking at those therapies. We have integrated them. We have the most successful, total integrated program in the world today. We have an ultramodern, 130-bed hospital that is fully equipped on anybody's standards.

We have nuclear medicine. We have all the diagnostic aids that are required. The point is that we do integrate traditional therapy, but traditional therapy is not used exclusively. Alternative therapy is not used exclusively.

If one tries to use either of those modalities, you fail.

Senator PROXMIRE. Doctor, thank you very, very much. I appreciate this testimony, and I am very glad that you emphasize the preventive element here. It needs much more emphasis than it has received in the past.

Thank you, sir.

Our next witness will be Samuel Wallace, medical researcher, U.S.A. health care practitioner, Brazil.

Mr. Wallace.

STATEMENT OF SAMUEL B. WALLACE, MEDICAL RESEARCHER U.S.A. HEALTH CARE PRACTITIONER, BRAZIL

Mr. WALLACE. My name is Samuel Wallace. I was a medical practitioner in Brazil and I am a health care researcher in Washington, DC.

I wish to testify about health care and how health care and medicaid can be improved through better health care procedures that will save lives and reduce costs.

In 1970 while in Brazil I discovered a cure for the common cold, influenza, and other respiratory illnesses using common FDA-approved antibiotics such as penicillin, tetracycline, terramycin combined with phenylephrine hydrochloride weak solution. This medicine was so effective that when applied nasally the time it took to cure the cold, influenza, and pneumonia was 3 days.

Since my discovery in 1970, there has been a considerable amount of research in the area of vaccines applied nasally and orally. Researchers in the United States, France, and Israel have all discovered that by applying vaccines nasally more antibodies, the disease fighting components of the human blood, are produced in the lung immune system.

However, there has been and still is a great reluctance on the part of the medical profession to apply my suggested treatment of antibiotics combined with nasal decongestants phenylephrine hydrochloride to the nose in order to treat respiratory illnesses and other diseases as they occur. I have also personally done a considerable amount of research on the immune system, particularly the B cell immune system which is the first responder to any serious illness.

My research, based upon data I developed in Brazil and based upon evidence presented by other researchers, indicates the lung immune system is the principal immune system in the human body, and that the system manufactures antibodies that go to all the other glandular systems; the pituitary glands, the mastic gland that controls the other glandular systems, the spleen, the adenoids, the synuses, the lymph nodes, as well as through the arteries and the vein blood—there are two separate systems—and that it is obvious that if one were to incorporate the lung immune system into therapy for many respiratory illnesses and other infective diseases that in properly utilizing this magnificent immune system the quantity of medicine needed to cure would be smaller and the time of cure would be shorter.

My findings in Brazil, applying antibiotic nosedrops, could indicate the amount of medicine used to produce a cure can be reduced to 25 percent, or less than the normal curative dosage by the physicians' desk reference to treat such illnesses as pneumonia, for example, and other illnesses, such as malaria.

I am, therefore, somewhat disappointed that my medical discovery has not been used to treat a wide range of illnesses and lung diseases including cancer. Dr. Umesawa, director of the Institute of Antibiotics, Ministry of Health, Tokyo, Japan—the world's foremost cancer authority—who has discovered thousands of antibiotics, many of which are now used in the treatment of cancer, discovered bestatin, an immunomodulator which when given orally produces twice the number of antibodies in the immune system than previously existed before its application.

This antitiotic, bestatin, is not immune suppressing, is nontoxic and have been used successfully to treat cancer in Japan.

My experience with penicillin in Brazil indicated that penicillin was the most potent of antibiotics in fighting both viral and bacterial infections. My tests for that medicine also indicated, according to the cure times published in the hearings of the House of Representatives in 1975, that when penicillin is combined in 1 percent solution the quantity of antibiotic used to produce a cure was lower than 25 percent of normal dosage and the cure times were reduced by the same amount.

This would indicate that there is five times more antibodies or antibiotic antibodies combined with antibodies in the B cell immune system of the lungs by this method of application and that the medicine enters the entire immune system far more rapidly than any other route of administration.

Further proof of this is indicated by the times this medicine takes to cure asthma. This can be tested in 1 day's time for asthma. It can be tested against viral fevers in 1 day's time.

I have begged the NIH. I have even talked before the NIH. I have explained the effects of this medicine for the treatment of asthma in 1 day's time and they still refuse to test it for asthma; 1 day's time.

They have adopted a derivative of the same medical formula, donnarubesin, which is toxic and an immune suppressant, rather than a streptomycin combination, a parent drug which I recommended, or the penicillin combined with the phenylephrine, a parent drug which is nontoxic and effective, far more effective. They won't test it.

Thus, as I was saying, my formula can be tested against asthma, viral fever for the reduction of fever. I treated innumerable fevers in Brazil successfully with the same formula. Both the NIH and the FDA have refused this, as I said.

It could also be used in preventative medicines. It could be used in the area of preventative care. We have the problem of the smokers and lung disease.

Now, if you see this diagram, you can see the lung immune system. It is a principal system. It is linked to all the glandular systems in the human body and these glandular systems help to produce antibodies, but primarily the capillaries which represent 100 square yards where the antibodies are formed in the human body.

The antibiotics can be applied through the nose, going in through lung cell system, and cures are produced much more rapidly than any other form of treatment.

My uncle was a famous physician in New York City. It would take him 2 to 3 weeks to cure pneumonia using antibiotics applied orally, which is a fine treatment. Applying this method, nasally, it takes 3 days' time.

Yet the NIH is unwilling to try it. The NCI is unwilling to try a safe form of the same formula that I recommended as treatment for lung disease; and it could be used in the treatment of all types of lung diseases and it could be used as a preventative.

If smokers who have emphysema, who have asthma, who have other lung conditions were given this medicine, this medicine would prevent many forms of cancer. So it could be instituted into a public health program.

But what about people working overseas that have limited resources and so on? Your medical missionaries, they could use this. What about people in developing countries? They could use this formula.

It's a very effective formula and it takes 1 day's time to test it.

PREPARED STATEMENTS

Senator PROXMIRE. Mr. Wallace, you make a very, very strong case. We appreciate it very much. We have your complete statement.

Mr. WALLACE. Yes; I gave you my complete statement——

Senator PROXMIRE. We'll review it for the record and we appreciate having it.

Mr. WALLACE [continuing]. And I tried to emphasize the major points——

Senator PROXMIRE. Thank you, sir.

Mr. WALLACE [continuing]. And the major points are that we have an immune system that is not being used and we have an antibiotic treatment that's the most effective in the world. It's not being used and they refuse to test it, simply refuse to test it.

Senator PROXMIRE. Well, there's a lot of logic in what you say. Thank you very much, sir.

Mr. WALLACE. Thank you very much. I appreciate the time that you've given me to testify.

[The statements follow:]

STATEMENT OF SAMUEL B. WALLACE

My name is Samuel B. Wallace, a medical practitioner in Brazil and a health care researcher here in Washington, DC. I wish to testify before your committee about how health care in the United States and as a result medicare can be improved while lowering the costs of such services to a reasonable extent. There are three possible approaches to this problem: (1) that of the Brookings Institute that suggests that health care should be more selective and that various facilities should be reduced substantially for the purposes of saving money with the health providers determining who should and who should not receive health care particularly among the poor and elderly. I reject this approach as cruel and barbaric and unnecessary; that it indicates a fundamental failure of the present U.S. health system; (2) that of Japan which has sustained a flourishing economy with a high rate of employment over a long period of time and who under the auspicies of great scientists, teachers, and physicians such as Dr Umezawa is now in the forefront of antibiotic therapy and research. (Japan has twice the cure rate for cancer as the United States); (3) that of Puerto Rico which enjoys commonwealth status under the American flag where Puerto Rican physicians trained in the United States of America, operate a highly competitive public and private health care system which delivers the best care available to even its poorest citizens. I would like to think that it would be possible to combine the best in the approaches of the last two systems, that of Puerto Rico and Japan, which should result not only in improvement in the quality of health care, but also improvements in medical education and medical research which should result in a redirecting of American health care to those goals to which such care was originally intended.

I hope in this paper to focus on the issue of how the quality of American health care can be improved because under the present system there is no guarantee that anyone rich or poor will receive the proper health care that he or she should receive when they are seriously ill. In America today there is entirely too much surgery, a general ignoring of the value of curative medicines, reliance upon painkillers and tranquilizers. Research in biogenetics is directed toward solving problems concerning how diseases can be manufactured rather than by applying science to the effort of searching for reasonable cures within the realm of medicine or pharmacology. Much of the great progress in developing good curative medicines has been ignored by medical scientist and physicians who are discovering that they can cure fewer and fewer diseases because of immune deficiency. I hope to show in this paper what my experience in Brazil taught me and that is that many of the incurable diseases are curable. We shall begin with cancer therapy.

Professor Goldstein at the Fronteers in Cancer Research hearings in 1979 candidly and courageously assessed the principle defects of cancer treatment. He pointed out that most forms of chemotherapy, radiation, and even surgery were immune destructive and toxic (poisonous), that oft-times the patient died because of such treatment even before the disease would have taken its normal course. For example, in lung cancer therapy, the lung of the cancer patient is often removed which means that most of his lymphatic and capillary lung tissue vital for all functions of life including the immune system is removed. Present lung cancer mortality—95 percent. Many forms of therapy use toxic chemicals which destroy the patient's thymus and other vital organs such as the liver and the spleen which produce B cell antibodies.

In 1975 before the Subcommittee on Health, I proposed a new antibiotic treatment for a wide range of viral and bacterial illnesses which was composed of a synthetic immune hormone similar to adrenalin combined with penicillin, tetracycline or streptomycin which was applied nasally. I indicated that this formula could cure a wide range of illnesses in a very short period of time using a very small quantity of medicine. (Three days for pneumonia, 1 day for asthma, 10 days to 2 weeks for meningitis.) In July 1979, I submitted a new cancer treatment that was based on my work in Brazil and 4 years additional medical research at the National Medical Library in Bethesda. I indicated that the incorporation of this therapy into a more scientific approach of treating the cancer patient's cancer infection directly was well as treating those immune systems closely related to the cancer infection would improve the cure rate for cancer patients considerably. My suggested therapy not only left the cancer patient's immune system intact, but actually strengthened it as well as also treating directly the area of the cancer infection with antibiotics that were safer and effective according to the FDA. Thus, the treatment for lung cancer that I recommended treated the area of the lung infection directly with antibiotics as well as the immune systems directly involved. In the case of lung tumors, special surgical procedures would be necessary together with floroscopy to ensure that actual cancer tumors were treated directly with antibiotics, for example.

The National Cancer Institute refused to consider or test my suggested treatment for cancer, but chose instead to invest its resources in bioengineering, spending over $1 billion in interferon research and bone marrow transplants both of which have had a very high rate of failure. The NCI did test derivatives of my formula that were toxic and immune-suppressing. To understand my therapy let us look at the lung immune system.

Antigen (bacterial, viral or toxic) enters the human body through the lung respiratory system and other systems where they are challenged by immune cells which produce antibody and other immune cells. The B cells produce antibodies in the upper bronchius airways passages and in the lower lung capillaries. The B cells and antibodies pass from the lung capillaries into the lung lymph node and from their through the thoracic duct into veins linked to the heart and from the heart through the arteries back to the lymph nodes. The lung lymph nodes are also linked directly to all the other lymph nodes and to the liver and the spleen. It is important to note that the lung immune system is the only immune system in the human body that is linked to all the other systems and is the principle immune system in the human body. Thus it is linked to both the arterial and veinular blood systems, to liver and spleen and thymus and the lung lymph node is linked to all the peripheral lymph node systems.

It is a tragedy that medical science neglects the lung system in treating illnesses because the lung immune system is nature's most powerful tool in fighting against infections both directly and indirectly. Thus lung cancer is not treated with curative medicines being administered directly to the nose which is linked directly to the lung immune system nor by the direct injection of antibiotics to the area of the tumor infection. Yet the slow acting small cell carcinoma, when it has infected the lungs, acts quite rapidly once it has entered that system. And many inaccessible infections could be treated through treatment applied through the nose to the lung immune system. Particular B cell antibodies such as the Ig, IgA and IgE of the bloods white cells respond differently to antigen. Thus the Ig cells respond in the lower lung respiratory tract and the IgA in the upper bronchius airways passage tract. And the IgE responds to allergy encountered in the nose. All antibody are composed of light and heavy chains with the heavy chain being stable and the light chain allowing the antibody to combine with antigen or infective substances, with other antibodies or cells, and with synthetic antibodies (antibiotics), hormonal substances and other chemicals. The IgA antibody cells act very rapidly to fight respiratory infection in the upper respiratory bronchial tract, the Ig's act much slower to fight more severe infections in the lower lung tract. And the IgE's are the most swift in fighting allergies such as asthma. This is confirmed with my own studies in testimony before the Subcommittee on Health, 1975. Thus time of cure for pneumonia (lower tract infection) applying antibiotics in phenylephrine hcl solution as nosedrops was 3 days as compared to 2 weeks normal cure time. Asthma treatment resulted in a cure in 1 days time. Influenza 1 to 3 days.

The cancer treatments, interferon, and bone marrow transplants are basically B cell or B cell antibody forms of treatment. Interferon has a low-cure rate against ordinary viruses such as the common cold or influenza. Bone marrow transplant which is basically a B cell transplant since all T cells have to be removed in order to prevent graft host rejection has a failure rate of over 90 percent of the treatment of leukemia. For these two biological treatments the NCI has spent well over $1 billion. The treatment that I proposed using ordinary antibiotics has a cure rate of over 90 percent for most respiratory and viral illnesses and it is a B cell treatment that improves that immune system as well as other immune systems in the patient's body without putting the patient at risk. It is also the only form of treatment that introduces curative medicines into both the arterial and veinular circulatory systems simultaneously. It is possible to test this in a days time against viral fevers.

Dr. Good of the University of Minnesota noted that most autoimmune diseases and neoplasm shared the common characteristic of defects in either the B cell or the T cell immune system. Thus Bruton's disease which characteristically is accompanied by a lack of immunoglobulin (antibodies) is in many instances followed by acute leukemia. There are similar analogies for other autoimmune diseases. It has been suggested by Dr. Lauria et al. in the British Journal of Haematology 1983 that T cell abnormality in B cell leukemia is not directly responsible for B cell or its antibody absence, but is probably due to a defect in T cell helper cells that produce B and T cell interactions in response to antigen.

One advantage of treating the principle immune system in the human body, the lung system, is that that system is related to all the other immune systems in the human body and that a small amount of curative medicine acts as a catalyst that goes to all the glandular organs that regulate the immune system such as the thymus, the pituatary, the liver, and the spleen, as well as the lung and other lymph node systems. Thus when one immune system such as the B or the T system is out of balance and is producing more or one type of immune cells than is healthy causing autoimmune reactions a little bit of antibiotic in proper solution applied to the principle lung immune system tends to reach all other systems and causes those systems to return to some semblance of equilibrium or balance. Therefore, in cases where only the most potent chemicals were deemed necessary treatment of the immune system before and after such harsh treatment could result in some restoration of the immune system provided that system had not been totally destroyed.

Evidence that this is true is clearly established by Dr. Umezawa's studies on bestatin which act against B cell defects and T cell defects causing an increase in cells each time, (See Dr. Umezawa in book "Recent Cancer Research" vol. 75 edited by Mathe, 1980), "Screening of Small Molecular Microbial Products Modulating Immune Responses and Bestatin," pp. 115–125 where Japanese and European doctors indicted that oral administration of bestatin increased the percentage of T cells and B cells. Of course were this medication tc be applied nasally in weak phenylephrine hcl solution by nose to the lung immune system the results, it would seem, would be more favorable and would tend to bring immune systems out of balance into balance.

Dr. Good also noted that the autoimmune alloallergic diseases such as arthritis are caused by a fever causing infection as well as a lack of some antibodies and an over abundance of IgW antibodies. The fact that my formula, as reported in 1975, cures the rather simple alloallergic disease asthma, a long list of respiratory illnesses and viral illness and glandular illnesses. I would suggest that it might be applicable to arthritis. All of this brings us to the selection of proper anticancer drugs which also relates to the proper curative medicines in general because this is the most important problem in medicine today as my experience has clearly indicated what I have also observed, and that is the American medical profession, although having some fine exceptions, is not geared to the dispensing of the proper curative medicines under ordinary circumstances despite the great advances made by the pharmaceutical industry since 1947. It also appears that that industry despite its advances in medical science is more interested in selling panaceas or painkillers than it is in selling the proper curative medicines. And it is such practices that have prolonged illnesses and raised medical expenses to such unprecedented levels.

The National Cancer Institute has in its system of selection of anticancer drugs demonstrated a lack of competance and obtuseness that clearly indicates a lack of interest in the welfare of the cancer patient and the proper promotion of appropriate cancer research. I think that this is a splendid example of what happens when the noble goals of medicine are foresaken for the ephemaral promises of pure research. The stages of drug development are too long and there is also an arregance in trying to prejudge the work of established scientists of other countries such as Japan, England, France, Germany rather than accepting their work at its stated value in most cases. I shall give you an example of work that should have been thoroughly tested and evaluated and if found favorable used.

Several years ago, I submitted to the National Cancer Institute the antibiotic formula that I had developed and tested against a wide range of viral and bacterial illnesses in Brazil. Some officials of the FDA acknowledged that my formula composed of ordinary antibiotic in weak solution of phenylephrine—hcl was safe. I had previously indicated in testimony before a House Health Subcommittee that the time of cure, the cure rate, and the small amount of medince used were extraordinary. The NCI refused to test this formula that was safe and immune enhancing and effective. Instead, the NCI after extensive animal and human tests took a derivative of one of the original antibiotics I had proposed that was toxic and immune suppressing and approved the highly questionable alternative. It so happens with few exceptions most anticancer drugs that the NCI tests and approves are toxic and immune suppressing. My question is why is the NCI unwilling to test anticancer drugs that are safe and that have a favorable cure rate when used against virus? The NCI also wasted $1 billion in developing interferon that is ineffective against virus.

SELECTION OF ANTICANCER DRUGS FOR TESTING AND THERAPEUTIC USE

I would like to suggest a more flexible and expedient methods of testing anticancer drugs. Those drugs which the NCI can truthfully categorize as toxic and immune suppressive would remain subject to phase I, II, and III trials. New drugs that had promising characteristics in terms of their pharmaclogical, toxicological, and immunologicial and antitumor characteristics or a showing of other superior qualities and results compared to other drugs of a similar kind that were not toxic and not immune destroying or permanently immune suppressive would be given short tests on animals and then would be given closely monitored clinical trials on cancer patients with their informed consent. On the reasonable theory that finding a cure for cancer was more important than time-consuming tests which would prevent effective drugs from readily reaching the market. This would presuppose that the U.S. Government would continue to test batches of all such drugs for their quality and consistency. (The wise legislators who wrote the original Food and Drug Act required continual testing of antibiotics because they realized that weakened products would not have the same curative potency and could lead to all kinds of abuses in medicine.) Those drugs in particular the common antibiotics known to be effective for a wide spectrum of illnesses, viral and bacterial, would, in their original or compounded safer form, be tested without prior animal tests by testing immediately on cancer patients themselves with their informed consent.

SUMMARY

It is a well-known fact that medicare costs are soaring. I have mentioned in this testimony two other health care systems that of Puerto Rico and Japan, one primarily a public health system and the other a private health care system. Both have apparently achieved better results at lower costs than the American Health Care Industry. Both other systems rely heavily on antibiotic medicines to cure many illnesses inexpensively. I have also attempted to develop evidence based on my own experience in Brazil where I discovered an antibiotic formula that proved to be extremely effective in treating and curing a wide range of very difficult illnesses.

In contrast the American health system neglects the use of antibiotic therapy and relay heavily on painkillers and panaceas that have no curative properties and in general the use of such nostrums only serves to prolong serious illness to the point where extraordinary procedures are often necessary. The use of curative medicines is far less costly and in addition to curing the illness often in the process also causes the pain to cease.

I have also suggested new methods of drug evaluations for anticancer drugs particularly with respect to medicines long known to be safe and effective. And it probably would have been wise to mention patent law reform so that pharmaceutical manufacturers can patent more readily new combinations of old drugs for new uses.

I would like to add that it is my opinion that the medical profession is in general too tied up with seeking the precise cause of the illness—usually a microorganism among a trillion others and thus do not devote their energies toward finding what can actually cure an illness, usually a pharmacological product (medicine) of some type. Both research and therapy needs to return to the basics. M.D. researchers need more hands on clinical time, sometimes even testing their medical theories on viruses in people rather than on mice in the laboratory or participating in long hours of gene splitting projects only. Military medical personnel need experience in actual emergency medicine which can be gained in any general hospital emergency ward or shock trauma unit. And research institutes of great renown receiving large public and private grants need to devote some of their efforts to the practice of medicine in poor communities in order to help upgrade health care in areas of exceptionally high mortality. There are no easy answers, but improvements can be made.

My name is Samuel B. Wallace. I was a medical practitioner in Brazil and I am a health care researcher in Washington, DC. I wish to testify about health care and medicare can be improved through better health care procedures that will save lives and reduce costs.

In 1970 while in Brazil, I discovered a cure for the common cold, influenza, and other respiratory illnesses using common FDA approved antibiotics such as penicillin, tetracycline, terramycin combined with phenylephrine hcl in weak solution. This medicine was so effective that when applied nasally, the time it took to cure a cold, influenza, and pneumonia was 3 days.

Since my discovery in 1970, there has been a considerable amount of research in the area of vaccines applied nasally and orally. Researchers in the United States, France, and Israel have all discovered that by applying vaccines nasally—more antibodies—the disease fighting components of the human blood are produced in the lung immune system.

However, there has been and still is a great reluctance on the part of the medical profession to apply my suggested treatment of an antibiotic nasal decongestant or phenylephrine hcl to the nose in order to treat respiratory illnesses and other diseases as they occur.

I have also personally done a considerable amount of research on the immune systems and particularly the B cell immune system which is the first responder to any serious illness. My research based upon data I developed in Brazil and based upon evidence presented by other researchers indicates that the lung immune system is the principal immune system in the human body and that that system manufactures antibodies that go to all the other glandular systems, the pituitary glands, the spleen, the adenoids, the sinuses, the lymph nodes as well as through the arteries and vein blood systems. And that it is obvious that if one were to incorporate the lung immune system into therapy for many respiratory illnesses and other infective diseases that in properly utlizing this magnificent immune system that the quantity of medicine needed to cure an illness would be smaller and the time of cure shorter. My findings in Brazil applying antibiotic nosedrops clearly indicate that the amount of medicine used to produce a cure can be reduced to 25 percent or less than the normal curative dosage recommended by the physicians' desk reference to treat such illnesses as pneumonia, for example. I am, therefore, somewhat disappointed that my medical discovery has not been used to treat a wide range of illnesses and lung diseases including cancer.

Dr. Umezawa, director of the Institute of Antibiotics Ministry of Health, Tokyo, Japan, the world's foremost cancer authority who has discovered thousands of antibiotics many of which are now used in the treatment of cancer today, discovered bestatin an immunomodulator which when given orally produces twice the number of antibodies in the immune system than previously existed prior to its application. This antitiotic, bestatin, is nonimmune suppressing and is nontoxic and has been used to successfully treat cancer in Japan.

My experience with penicillin in Brazil indicated that penicillin was the most potent of antibiotics in fighting viral and bacterial infections. My tests for that medicine also indicated according to the cure times published in hearings before the House of Representatives, that when penicillin is combined with 1 percent solution that the quantity of antibiotic medicine used to produce a cure was lower than 25 percent of normal dosage and that the cure times were reduced by the same amount. This would indicate that there is five times more antibodies or antibiotics combined with antibodies produced in the B cell immune system of the lungs by this method of application and that the medicine enters the entire immune system far more rapidly than by any other route of administration. Further proof of this is indicated by the time it takes this medicine to cure asthma which is in 1 days time and the time it takes to reduce tropical viral fevers (1 day) as well as to cure such fevers 3 days. All of these facts indicates that by treating the principle immune system of the human body, the lung immune system, which is linked to all the other immune systems. That cures for many types of bacterial and viral illnesses can be realized in far shorter periods of time using far smaller quantities of medicines.

Thus my formula when properly applied can be tested against asthma and viral fever (for the reduction in fever) in 1 days time. Both the NIH, NCI, and FDA refuses to test this formula. I think that this is shameful particularly when there are so many diseases such as asthma, influenza, cystic fibrosis, viral fevers that the medical profession says are incurable that can be cured by the proper application of curative medicines such as my formula as compared with those medicines that the medical profession recommends—painkillers. I would suggest that the Congress that appropriates so much money for medicare and medicaid funding has got to obtain some reasonable assurance that patients when ill can receive curative medicines and in particular the antibiotics. If the doctors are unwilling to prescribe the common antibiotics, then Congress should abrogate the monopoly that the medical profession has in prescribing and dispensing such medicines and that authority should be given to nurses and pharmacists as well. My experience in Brazil and my medical research in this country both indicate that making the antibiotic curative medicines available to the sick is the best way to save lives and lower health care costs.

Japan and Puerto Rico have highly diverse health care systems. One which is private practice oriented (Japan's) and the other (Puerto Rico's) publically oriented (providing health care for the poorest of its citizens). Both provide quality health care at lower prices and both rely on the use of antibiotic medicines that are common and curative medicines rather than upon painkillers which eventually lead to extraordinary procedures and higher health care costs because the illness is not properly treated when it is first encountered.

I, therefore, think that it is up to the Congress to give the American people some assurance that the medical profession will prescribe the best curative medicines available which in many many instances are the common antibiotics such as penicillin, tetracycline, streptomycin, terramycin and amplicillin—a safe derivative of penicillin. These medicines are curative, safe, and effective when given to sick patients. It is up to the Congress to guarantee that such medicines are available to the sick, rather than painkillers which suppress the symptions, but do not cure the illness itself.

STATEMENT OF GRACE POWERS MONACO, J.D., NATIONAL LIAISON CHAIRPERSON, CANDLELIGHTERS

Senator PROXMIRE. Very good. Our next witness is Grace Powers Monaco, J.D., national liaison chairperson, Candlelighters.

Dr. Monaco, I have to leave. A much more distinguished Member of this Senate, Dan Inouye, will take over.

Senator INOUYE [presiding]. Thank you.

Dr. MONACO. Good morning, Mr. Chairman. I have one message this morning, really.

As I think the members of this committee know, I don't come and testify unless I think things are going a little bit awry. For the last several years, I have felt very clearly that the National Cancer Institute's program has been going in the directions it should go in in terms of cancer in children. For that reason my face has not darkened your door.

However, I did have to make an exception this year, and the exception comes because I want this committee to understand very clearly why the treatment of cancer in children is different from the problems that adults have and why we deserve a slightly different type of approach, which is already in place but which is not being funded correctly or appropriately by the Cancer Institute.

We are only 1 percent of the cancer problem although we are the second leading cause of death in children in this country. For that reason, we can't have a Cancer Institute, a cancer center, an enormous research center in every child's back yard that has cancer.

We have had to find ways of delivering excellent care to our children dispersed over wide areas of the country; and I think you would be familiar with that problem. For this reason, a very special program developed. It's called the clinical cooperative trial programs.

Predominently it's the POG Program and the CCSG Program; POG that radiates out of the Missouri area, CCSG that radiates out of the lower California area. Through the POG and CCSG programs, through their clinical cooperative programs that deal with research and the clinical application of that research, as well as through the cancer control outreach activities we have made sure that two-thirds of the children with cancer in this country are part of a research program; have access to, through either outriders or education or communication and education programs, centers of excellence when they need it; that the doctors in the communities that are treating them are being brought up to date when they need it; and when, of course, the children need to be staged, evaluated, reevaluated or have new therapies tried on them they have access to one of the hubs at the centers of this wheel nearest their homes to treat them.

The Director of the NCI told Congressman Natcher that he had no intention of funding the grants that had been approved for these clinical programs at the level at which tne peer review groups recommended them; and that is all we are asking.

We are saying, Divita fund good research that has been approved up and down the kazoo by your own people at the level that they've asked for because right now we're talking about cuts of 20 percent a year in our children's programs and we're not going to have a situation in which I can come before this committee and say in another 10 years that when my daughter was diagnosed with nalcell acute lymphocytic leukemia in 1968 the cure rate for her cancer was under 10 percent and, today, it is 80 percent if we permit the clinical cooperation base that is in place now to erode, if we permit our children to slip away from excellent care, and if we permit those hubs to be cut off from all their spokes; and that is exactly what NCI is proposing to do.

They are really rather giving you gentlemen the finger, I would say, because they are saying, "We can do what we damn well please with your money," and really they're saying that unless you give them a couple of million dollars extra and earmark it for our kids, our kids can take a walk.

I don't want that and I don't think you want that.

One or two other tiny little points while I still have my gray life. I have practiced talking fast especially for this morning.

One of them is to bring to your attention on the heels of Mr. Bradford's statement about the need for prevention and the like that in 1974 it was the Candlelighters who came before these committees—in this part it was the authorization committees—that gave the testimony that put into place the Diet, Cancer, and Nutrition Program.

You haven't heard me talk about that because we are convinced that that program is working well and it is now up to a very good funding level. We did this because we believe very strongly that we need a scientific base and a scientific answer to all those questions about cancer, be they relating to nutrition or other purposes, that are floating around out there.

Through that program, through the Orphan Drug Program which was put in place, which now gives us an opportunity to fund clinical trials on different types of treatments that have not been widely accepted by the pharmaceutical companies, I think we are well on the way in the prevention area.

I would just correct one small point in my own statement for the record, and that is on the first page I mention that 54 percent of our children with leukemia on nationwide averages are surviving. It's 50 percent. Of course, the countrywide figures in centers of excellence of curing children from cancer, completely rolled in now, no matter where they're treated, is 49 percent.

When we're dealing with centers of excellence and trying to get this extra one-third pushed into the clinical cooperative group so that excellence can be prevalent throughout, we feel very strongly that we can bring that well over 60 percent within the next 5 years.

Thank you very much for your time. I'd be happy to answer any questions that you have.

Senator INOUYE. Thank you very much. That was not only forceful, but fascinating.

Can you tell this committee why the Institute is adamant in not spending the money?

Dr. MONACO. I do not pretend to be a seer, so I cannot say that I'm inside anybody's minds. Perhaps because children are more attractive and children may be sexier, they may think that we can raise the money somewhere else to do this work.

But we prefer to have it done under the light of the peer review process that is in place at NCI; and I think we also prefer to have ourselves recognized as the laboratory we have always been because the kinds of things that we've learned through the children have later been applied to the adults.

What do they have on their minds? I will say one other thing that is probably less kind.

We are only 1 percent of the cancer problem. Politically, we're not as big a power base. I know that the CCOP Program, which is the Community Cancer Oncology Program, is very important to the adult community and absolutely essential.

So that the kinds of good news that we have in childhood cancer and that we've already achieved through our clinical cooperative programs can be translated into the adult community; but we're not appropriate for CCOP and we have our own structure which serves us well.

Putting the emphasis on CCOP is fine, but not to the detriment of what the pediatric oncology people need. I think, Senator, we are not quite as politically sexy as the adult cancers; and I think perhaps it's time to remind people that we are where it's happened in cancer; we are where it will continue to happen; and that we cannot let ourselves be put on the back shelf and forgotten.

Senator INOUYE. I can assure the subcommittee will not put you on the back shelf.

Dr. MONACO. Thank you.

PREPARED STATEMENT

Senator INOUYE. Thank you very much. We will insert your complete statement in the record.

[The statement follows:]

STATEMENT OF GRACE POWERS MONACO, J.D.

My name is Grace Powers Monaco. I am National Liaison Chairman of the Metropolitan Washington Candlelighters. This association serves as the legislative arm of an international volunteer coalition of 218 groups of parents whose children have or have had cancer in 50 states and Australia, Canada, Chile, Denmark, England, France, Germany, Greece, Guatemala, Holland, India, Indonesia, Ireland, Italy, Mexico, Sweden, South Africa, East Africa, and New Zealand.

Children's cancer treatment successes have led the good news in cancer treatment for this decade. When my daughter was diagnosed in 1968, the possible cure rate for her cancer was less than 10%. Today the cure rate for acute lymphoblastic leukemia is 54% nationwide and 80% at centers of excellence in treating pediatric cancers.

A study by Dr. Robert W. Miller and Frank W. McKay published in the Journal of the American Medical Association* tracked deaths from cancer among children under age 15 from 1950 to 1979. It showed in that period:

80% fewer deaths from Hodgkin's disease, a type of blood cell cancer;
68% fewer deaths from kidney cancer;
50% fewer deaths from leukemia and bone cancer;
32% fewer deaths from other immune system cancers; and
31% fewer deaths from all other cancers.

The 1970 survival rate overall for childhood cancers was 39%. Now over 54% are surviving their disease.**

*JAMA:251-(12) 156-7-70) March 1984
**American Cancer Society Statistics 1984

Data from 1980 show the mortality rates for leukemia and non-Hodgkin's lymphoma are still declining. But rates for Hodgkin's disease, bone sarcomas, kidney and other cancers seem to have reached a plateau.

Will the good news in childhood cancer continue? There is grave doubt if this Committee doesn't instruct NCI to stop its destructive, short sighted budgetary treatment of the mainstay of the progress in our children's cancers--the pediatric/adolescent clinical cooperative groups.

Dr. DeVita was asked by Chairman Natcher if he intended to fund the cooperative groups at the amounts recommended by the peer review process. He said No--unequivocally.

In real dollars, a static budget, not tied to peer review supported amounts, means that the pediatric clinical cooperative trials are suffering cuts of 20% a year or more.

What will this do to progress against childhood cancers? It is rather like our worries over the Social Security system - it is robbing the future of its promise.

To understand the damage posed by not fully funded pediatric cancer clinical cooperative programs, you have to understand the unique position of pediatric and adolescent cancers in the United States. We represent about 7,000 new cancers a year, only about 1% of the total number of cases of cancer.

Because of the small numbers of children and adolescents with cancer, this country does not have the resources to have treatment facilities and programs in every child's backyard.

CCOPs are not appropriate to pediatric/adolescent cancer due to our numbers. A radiotherapist in a community might be called on to treat a young child with Hodgkin's disease about once every 5 years, or a surgeon to remover an abdominal tumor once every 5 years. We recommend the development of cancer centers located less than 150 miles from small communities where all children with cancer could be referred for initial definitive therapy. Much of the subsequent chemotherapy could be given by the referring physician in close consultation with the regional pediatric oncology expert.

These groups serve as the hub of the wheel. Their close communication, cooperation, conferences, and coordination give us the benefit of a truly national program. Their efforts have made access to excellent major research and clinical programs, outreach and supportive care now a reality to 2/3 of children and adolescents with cancer. In reality, these groups are the equal in pediatric/adolescent cancer to CCOP. They are already delivering to the pediatric and adolescent cancer population the promise of access to first quality treatment and an expanded research base which it the premise and promise of CCOPs to the adult populations.

If their approved clinical cooperative group grants and their separate but equally essential cancer control programs are fully funded at the levels recommended by the peer review process, we should be able to expand that number of children enrolled in clinical studies so that over time, close to 100% of our children are tied into the communication, cooperation, trial, outreach and support programs of these groups.

These groups are the equivalent of our CCOPs. They are the proven and tested answer to progress and excellence in pediatric and adolescent cancer treatment. They are being slowly strangled. Without the information and activities supplied by these clinical programs, research progress and its clinical application would come to a standstill and new approaches to cancer cure may remain undiscovered, unthought, unexpressed.

All medical school based pediatric oncology programs should be members of Clinical Coop Trials. This will assure that all students, residents, etc. are at least aware of some of the problems of children with cancer and allow them to conceptualize working with a childhood cancer center if they are one of the "local" doctors. All of the children's cancer center should be medical school based if possible. Exceptions would be where there were no medical schools within 150 miles or the categorical institutions such as St. Jude.

Mr. Chairman, Members of the Committee, on behalf of all these parents across the country, I should like again to commend the Chairman and the members of this Committee for their many efforts and their understanding of our problems. Your dedication to the cause, the cure and the prevention of cancer encourages us to face the future with a greater degree of hope and peace of mind. Those of us who have lost children are grateful that your efforts to adequately fund the cancer research will be a memorial to them. And, those of us whose children are under treatment are grateful for the hope which research gives us in maintaining their well-being.

We gratefully acknowledge the part this Committee has played in this effort to conquer this dreaded disease. Thank you for permitting us to appear before you.

STATEMENT OF TIMOTHY R. TALBOT, JR., M.D., CHAIRMAN OF THE BOARD, ASSOCIATION OF AMERICAN CANCER INSTITUTES AND PRESIDENT EMERITUS, FOX CHASE CANCER CENTER

PREPARED STATEMENT

Senator INOUYE. Our next witness is the chairman of the board of the Association of American Cancer Institutes, Dr. Timothy Talbot. Dr. Talbot?

Dr. TALBOT. Thank you, sir.

Senator Inouye. We have received your full statement. It will be made part of the record. For that matter, all of the statements received will be made part of the record.

[The statement follows:]

STATEMENT OF T.R. TALBOT, JR., M.D.

It is a privilege for me to appear on behalf of the Association of American Cancer Institutes (AACI) of which I am currently the Chairman of the Board. I am also the President Emeritus of the Fox Chase Cancer Center in Philadelphia which, in alliance with the University of Pennsylvania, is one of the twenty comprehensive cancer centers in the nation.

I have been associated with our Center since 1957 and have been involved in the problem of cancer in a number of ways since 1946, so that I have observed the development of almost all of our existing biomedical knowledge. Therefore, you can understand why I have such a sense of great wonder at how much has been accomplished during my lifetime, and at the same time, a deep awareness of how much remains to be done. Above all else I can now enjoy a realistic sense of optimism regarding the future -- but only if we, as a nation, continue to support the biomedical research programs that now exist because of the wisdom of the Congress, including this committee.

We are hearing much now about what makes a nation strong. I submit that one of the important characteristics of a strong and stable society is the maintenance of support of wide-ranging research so that we are always at the leading edge of new knowledge. Only thus will our industry, our economy and our health be at the leading edge.

The cancer centers of the nation, which have developed in an expanded program since 1971, are one important facet of the national biomedical research effort, and are examples of a real "success story." Almost 60% of all NCI research grants are now held by the major cancer centers -- and this is because they have succeeded in obtaining these grants on the basis of intensive competitive review in the peer review system, which we favor and strongly support.

A significant number of the most important advances in cancer management and the relevant biomedical sciences have emanated from NCI supported cancer centers. Some examples of these advances are as follows:

> Recent work in many laboratories has revealed the existence of specific genes in both animals and humans that are called oncogenes — or cancer genes. These new findings provide real promise that some of the fundamental processes of cancer causation are being revealed. Cancer centers, including our own and others, have been prominent in this important field.
>
> You are probably aware of work done during the last few years on the discovery of the hepatitis B virus, its relationship to primary cancer of the liver, and the subsequent development, and marketing by Merck, of a vaccine to prevent hepatitis — thus creating a means of preventing one of the most common cancers in the world. This was largely established through work at the Fox Chase Cancer Center.
>
> The recent explosion of new work in the field of monoclonal antibodies, which we expect to have a big impact on both the diagnosis and treatment of cancer, has involved a number of cancer centers in both fundamental and applied aspects of the problem. This entire field has already shown practical results that promise new successes in both diagnosis and treatment, and the first examples of how this might be done have emerged from at least two cancer centers.

These advances and others have led to improvements in the treatment of a number of tumors and improvement in patient survival. Basic molecular and cellular biology research at these centers in now uncovering the fundamental processes that underlie the mechanism of carcinogenesis. In addition, through new diagnostic and therapeutic methods such as CT, NMR, neutron therapy, biologic markers, and many other methods which are being pioneered in cancer centers, direct applications and studies in humans are proceeding. None of this could have happened, nor will it continue to happen as it should, without the cancer center support grants (core grants) to which we have previously referred on several occasions before this committee and other committees of the Congress.

What do we need to do to assure that we will continue to make new advances — to continue to learn? Let me address one very important issue that needs to be attended to in order that progress will continue: There has been, for several years, a consistent pattern of administrative devices, that are best characterized as "administrative alchemy," that were constructed with the supposed purpose of preserving more money, during the restrictive budget, for R-01 and P-01 grants for research. These have included, for example, repeated recommendations to reduce indirect cost allowances "because they siphon money away from research". They have included an attack on core grants and centers for the same supposed reason. There has also been a long downward trend in the support of renovations and new advances in scientific instruments, to the point of an almost certain catastrophic crunch in the entire scientific enterprise.

All of these oft-repeated proposals have already had one consequence -- the erosion of the stability and governance of the institutions, that are the household of our national scientific endeavors. A further consequence is the lack of confidence of our young biomedical scientific pool, leading to a diminution of our ability to bring the best young people to careers which they believe that they can no longer depend upon with reasonable assurance. This is especially true in the field of clinical research, and this problem is one that requires further study.

Core grants have been a useful mechanism to partially correct these deficiencies. It will be a tragedy if they are not endorsed and supported at both Congressional and Administrative levels.

We all owe it to ourselves and to the nation to continue to search hard for corrections to this fragility of our institutions that support research. Not an easy task, but it is the most important one we face in this critical facet of our national life. One cannot do modern research in an unheated garage. Therefore, it is clear that: "5,000 grants do not stability make" — and core grants, often under attack by alchemists, are the best example yet found to make a realistic beginning in doing what we need to do in order to provide the necessary infra-structure for biomedical research.

I should also like to point out that there is now an excellent and realistic geographic distribution of cancer centers, and of new clinical trial programs associated with them, throughout most of the nation. There are also excellent communications networks, designed to inform the public about the availability of cancer treatment, and to inform physicians about the existing options. (See attached maps.)

On November 17, 1983, the House of Representatives agreed on authorization language concerning cancer centers. In section 410, page H10267 of the Congressional Record for November 17, 1983, dollar amounts were authorized as shown below:

> "(2)(A) For the National Cancer Institute (other than its programs under section 413 and 415), there are authorized to be appropriated $1,163,000,000 for fiscal year 1984, $1,221,000,000 for fiscal year 1985, and $1,300,000,000 for fiscal year 1986."
>
> "(B) There are authorized to be appropriated for the programs under section 413 — $64,000,000 for fiscal year 1984, $74,000,000 for fiscal year 1985, and $84,000,000 for fiscal year 1986."

On page H10285 is bill report language as follows:

> "Section 415 requires the NCI to provide core support to a minimum of 55 national cancer research and demonstration centers in each of fiscal years 1984, 1985, and 1986. Cancer center core grants provide central support services and highly specialized laboratory services that are most appropriately provided on a common basis to several investigators working in close proximity within a cancer center."
>
> "The earmarking of support for a minimum number of cancer research and demonstration centers indicates strong support for the cancer center core grant program. The requirement that a minimum of 55 cancer centers be supported in each of the next three fiscal years is intended to be a floor and not a ceiling on the number of centers that may receive support."
>
> "Requiring that the Director of NCI maintain core grant support for at least 55 centers is intended to assure maintenance

> of a minimum level of support for the institute's centers program during the next three fiscal years. It is intended that this minimum level be maintained both in terms of the number of centers as well as the relative proportion of funding allocated to the centers program in contrast to other institute activities. This section should not be construed to imply or confer a funding entitlement to any individual center or group of centers. It is expected that the award of core grants will be based solely upon the scientific merit of each application as determined by appropriate peer review."
>
> "The proposal also extends the support period for cancer centers from three years to five years and removes the annual limitation on support for individual cancer centers."

The Senate has not, as you know, acted on the authorizing legislation but it is our hope that the provisions of the House passed bill will be accepted by the Senate or be accepted in the Senate-House Conference. We know that in the past this committee's support has been just as strong as that of the Authorization Committee.

Last year the Congress directed that the NIH should fund grants at the level of the budgets approved by peer review. The NIH then decided that this directive would apply only to R-01 and P-01 grants, thus excluding core grants for centers, and grants for cooperative groups. We urge that this committee take appropriate action to ensure that cancer centers support grants are funded at levels that are recommended by peer review, and suggest the following bill report language:

> "Core grants are essential for the stability and continued excellence of cancer centers, and they directly enhance the effectiveness of R-01 and P-01 supported research programs that are conducted at these centers. Therefore, there should be no distinction between R-01 or P-01 grants and core grants with respect to their levels of funding. It is vital that core grants be funded at levels that have been recommended by peer review in precisely the same manner, and to the same degree, as the R-01 and P-01 grants."

We recommend, Mr. Chairman, that the NCI be provided with a total of $1.3 billion for fiscal 1985, which after careful study, we do believe to be a realistic figure to keep the present machinery in operation. The NCI by-pass budget requested $1,189,000,000, which we do not believe is adequate to meet even the existing needs.

We have arrived at the figure of $1.3 billion in the following manner: We have added to the President's budget the standard deflator factor, which is generally accepted to be about 10%, plus about 5% for growth.

We should like to draw special attention to the fact that the President's budget contains $1 million less than the 1984 budget for cancer centers. We strongly urge that this be increased from $78,000,000 to $90,000,000 for fiscal 1985. This figure is arrived at by applying the deflator factor plus growth, as above. (A copy of the President's budget for the NCI is attached, with the line for cancer centers marked in yellow.)

In addition, however, there is now considerable public discussion by the NCI administration that there may be new cancer centers approved. We do not see the wisdom of doing that within the current budget restrictions and suggest that there be added $4,000,000 more to provide for that possibility, which we assume would be based upon peer review.

Finally, Mr. Chairman, all of us are grateful for the careful attention and support that has been given by this committee to cancer research over the years, and especially for the excellent budget you provided to the NCI last year.

National Cancer Institute

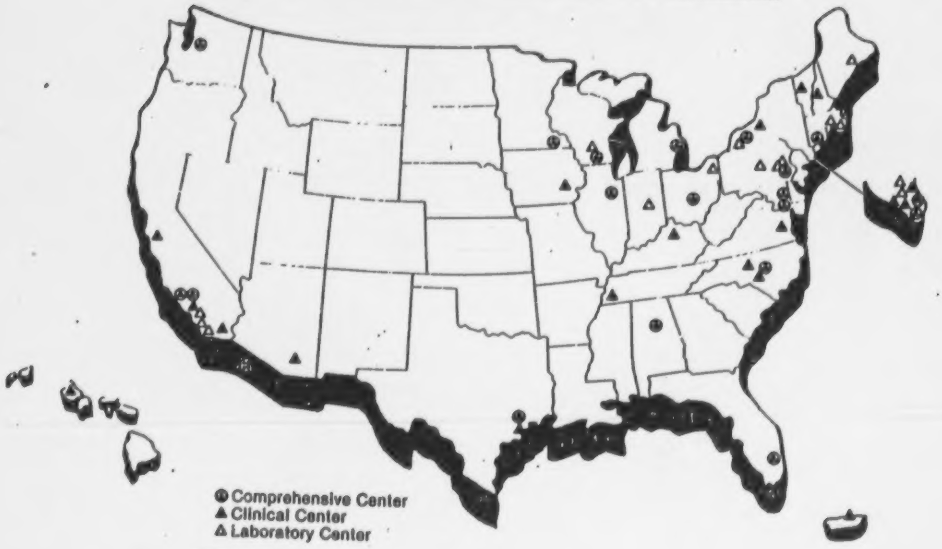
Budget Mechanism

(Dollars in Thousands)

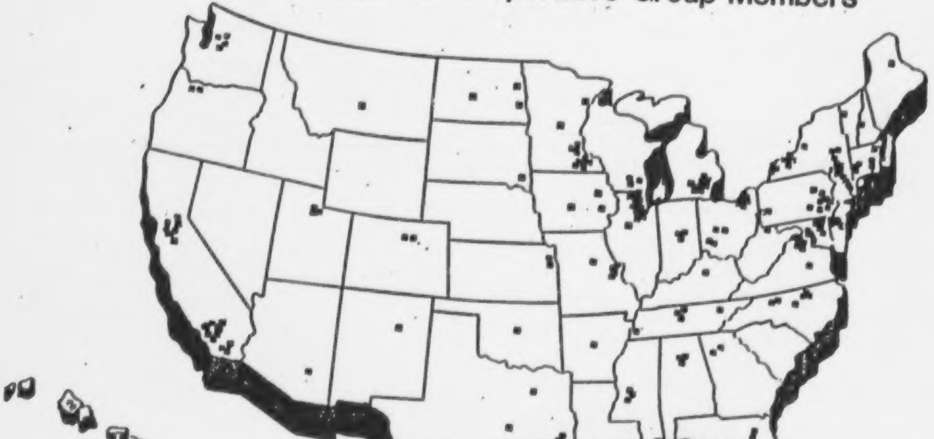
	1983 Actual		1984 Estimate		1985 Estimate	
	No.	Amount	No.	Amount	No.	Amount
Research grants						
Research projects:						
Noncompeting	1,927	$287,425	1,960	$ 312,531	2,017	$ 344,209
Administrative supplemental	(106)	6,439	(140)	6,325	(140)	6,325
Competing						
Renewal	356	57,084	368	80,671	343	75,302
New	527	55,333	555	70,822	534	71,003
Supplemental	3	110				
Subtotal, competing	886	112,527	923	151,493	877	146,305
Subtotal, research projects	2,813	406,391	2,883	470,349	2,894	496,839
Research centers	60	77,755	59	79,000	59	78,000
Other research:						
Research career program	123	4,992	124	5,627	118	5,627
Organ systems	1	591	1	750	1	750
Cancer education program	57	4,984	88	6,614	61	5,000
Cooperative clinical research	267	44,904	255	46,956	255	46,956
Minority biomedical support	—	2,087	—	3,000	—	3,000
Other research	31	3,437	49	3,500	35	3,000
Subtotal, other research	479	60,995	517	66,447	470	64,333
Total, research grants	3,352	545,141	3,459	615,796	3,423	639,172
Training 1/						
Individual awards:						
Noncompeting	83	1,630	110	2,100	74	1,736
Competing						
New	78	1,379	36	681	75	1,495
Subtotal, individual	161	3,009	146	2,781	149	3,231
Institutional awards:						
Noncompeting	1,101	16,689	1,138	21,080	594	11,702
Competing						
Renewal	188	3,499			438	8,342
New	33	736				
Subtotal, institutional	1,322	20,944	1,138	21,080	1,032	20,044
Total, training	1,483	23,953	1,284	23,861	1,181	23,275
Research and development contracts	423	134,898	409	132,475	390	130,388
	Pos.		Pos.		Pos.	
Intramural research	1,471	174,000	1,471	182,559	1,471	185,240
Research management and support	405	53,057	405	56,827	405	57,116
Cancer control	95	53,569	95	63,651	95	63,878
Construction	—	3,000	—	2,110	—	2,000
TOTAL	1,971	987,618	1,971	1,077,279	1,971	1,101,069

1/ Numbers are full-time training positions.

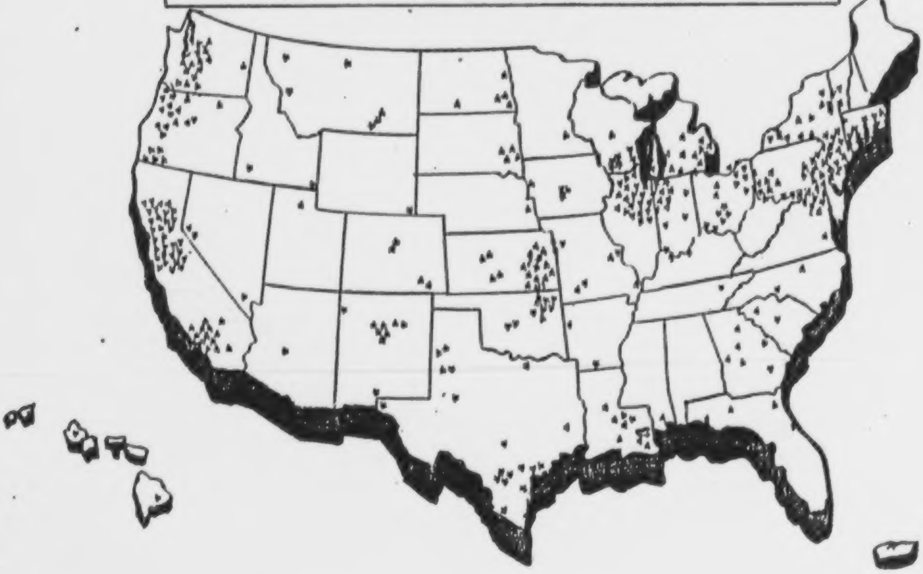
Location of Cancer Centers

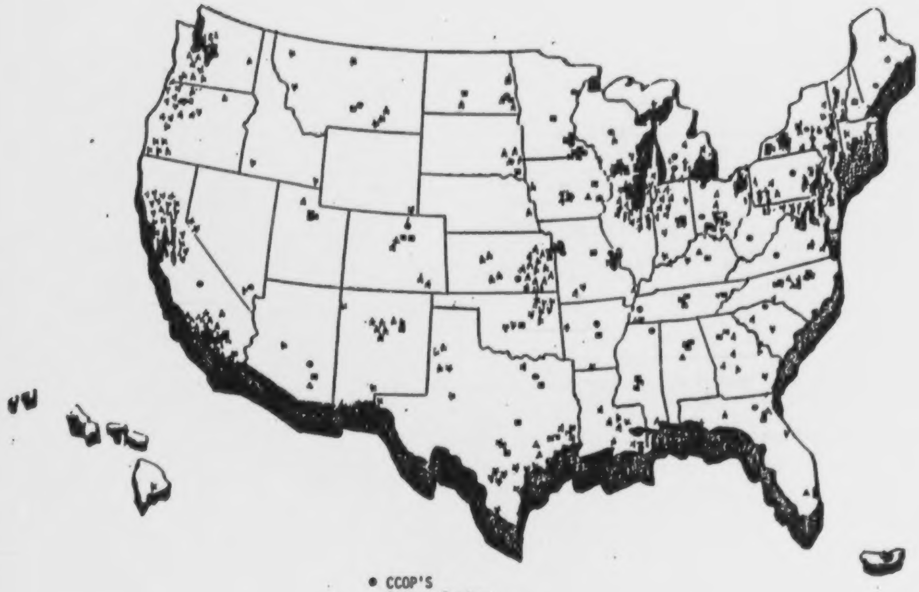

⊕ Comprehensive Center
▲ Clinical Center
△ Laboratory Center

Location of Cooperative Group Members



Location of Organizations Participating in the Cancer Control Outreach Programs of the Cooperative Groups

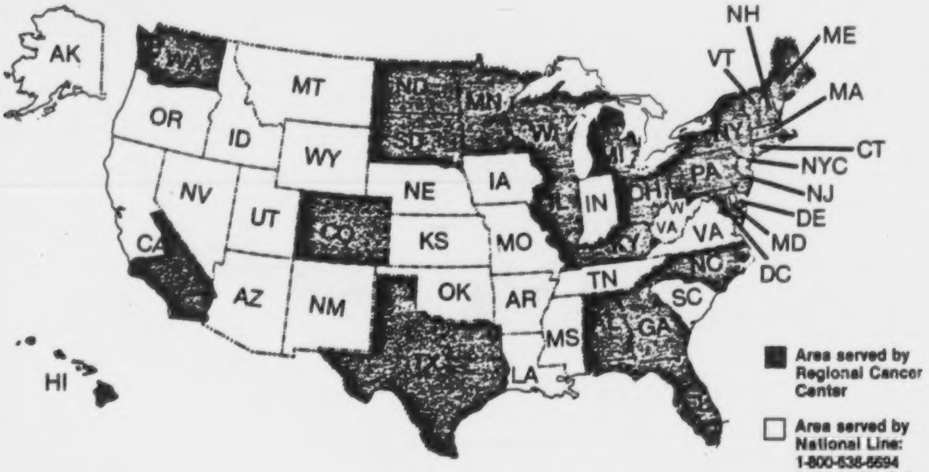




● CCOP'S
▲ Cancer Centers
■ Cooperative Group Members
★ Cooperative Group Outreach Program Participants

Cancer Information Service

The Public's Link to Cancer Information


AK
WA
MT
OR
ID
WY
ND
SD
MN
WI
MI
NV
UT
CA
CO
NE
KS
IA
MO
IL
IN
OH
KY
WV
VA
PA
NY
NH
VT
ME
MA
CT
NYC
NJ
DE
MD
DC
NC
SC
TN
AZ
NM
OK
AR
MS
AL
GA
TX
LA
HI
■ Area served by Regional Cancer Center
☐ Area served by National Line: 1-800-638-6694 (except Alaska)

Alabama	1-800-292-6201
Alaska	1-800-638-6070
***California**	From Area Codes (213), (714), (619) and (805): 1-800-252-9066
Colorado	1-800-332-1850
Connecticut	1-800-922-0824
Delaware	1-800-523-3586
District of Columbia (Includes suburbs in Maryland and Virginia)	636-5700
***Florida**	1-800-432-5953
***Georgia**	1-800-327-7332
Hawaii	Oahu: 524-1234 Neighbor Islands: Call Collect
***Illinois**	800-972-0586
Kentucky	800-432-9321
Maine	1-800-225-7034
Maryland	1-800-492-1444
Massachusetts	1-800-952-7420
Michigan	1-800-482-4959
Minnesota	1-800-582-5262
New Hampshire	1-800-225-7034
***New Jersey** (Northern)	800-223-1000
New Jersey (Southern)	800-523-3586
New York State	1-800-462-7255
***New York City**	(212) 794-7982
North Carolina	1-800-672-0943
North Dakota	1-800-328-5188
Ohio	1-800-282-6522
Pennsylvania	1-800-822-3963
South Dakota	1-800-328-5188
***Texas**	1-800-392-2040
Vermont	1-800-225-7034
Washington	1-800-552-7212
Wisconsin	1-800-362-8038

All other areas 1-800-638-6694

If you need information about resources in a state other than your own, call the Cancer Information Service serving your area for proper referral.

*** Services also available in Spanish**

August 1982

Dr. TALBOT. Thank you, Senator. I shall be addressing primarily the issue that you're holding in your hand, and I shall attempt to be as brief as possible.

First, I'd like to remind the rest of the people in this room of what you already know, and that is that there is an excellent cancer center in Hawaii. I would like to express thanks for the courteous attentiveness of your staff, especially Dr. de Leon.

I am currently, as you have said, the chairman of the board of the American Association of Cancer Institutes and I'm president emeritus of the Fox Chase Cancer Center, which Dr. Durant who testified earlier today has succeeded me in. We are one of the comprehensive centers in this Nation along with an alliance with the University of Pennsylvania.

I've been associated with this problem of cancer and with our centers since 1957 and with the problem of cancer since 1946 so that I've observed the development of almost all our existing biomedical knowledge. Therefore, you can understand why I have such a sense of great wonder at how much has been accomplished during my lifetime and, at the same time, a deep awareness of how much remains to be done.

The cancer centers of this Nation, which have developed in an expanded program since 1971, are one very important facet of the national biomedical research effort; and they are examples of a real success story.

Almost 60 percent of all National Cancer Institute research grants are now held by the major cancer centers and this is because they have succeeded in obtaining these grants on the basis of intensive competitive review in the peer review system, which we strongly support and endorse.

Let me address one very important issue that needs to be attended to in order that progress will continue. There has been for several years a consistent pattern of administrative devices that are best characterized as administrative alchemy, that were constructed with the supposed purpose of preserving more money during the restrictive budget period for RO-1 and PO-1 grants for research.

These alchemies have included, for example, repeated recommendations to reduce indirect cost allowances because they syphon money away from research. They have included an attack on core grants and centers for the same supposed reason.

There has also been a downward trend in the support of renovations and for scientific instruments to the point of an almost certain catastrophic crunch in the entire scientific enterprise.

We need, therefore, to put our attention to strengthening institutions. I'm sorry that Senator Proxmire isn't here because the idea of 5,000 grants producing stability by itself should get the golden fleece award.

What we need is to remember that core grants have been one type of device that can strengthen institutions and which, at the same time, can lend strengthening and stabilization to the entire RO-1 and PO-1 efforts.

What we now need to focus on, it seems to me, for the centers is the following: The administration's proposed budget, as you have in front of you, reduces the level of funding for cancer centers for from $79 to $78 million for the 59 centers, $79 million in 1984 and $78 million in 1985, at a time when all institutes were receiving at least a 2-percent increase.

Given even modest inflation there is simply no way that the level of programs can be sustained in the centers with this reduced amount. We recommend that the line item in the budget for cancer centers be increased from $79 to $90 million to allow for inflation and a modest 5 percent for growth.

Also, if new centers are to be funded this year, and the administration has indicated that it is considering that, then funding should be provided. We recommend an additional $4 million be added for this purpose if, in fact, that happens based on peer review.

We recommend that the National Cancer Institute be provided with a total of $1.3 billion for fiscal year 1985. Finally, the following:

Core grants are being funded now at approximately 15 percent less than the recommended peer review amounts. We, therefore, suggest the following bill report language:

> Core grants are essential for the stability and continued excellence of cancer centers and they directly enhance the effectiveness of RO-1- and PO-1-supported research programs that are conducted at these centers.
>
> Therefore, there should be no distinction between RO-1 and PO-1 grants and core grants with respect to their level of funding. It is vital that core grants be funded at levels that have been recommended by peer review in precisely the same manner, in the same degree as the RO-1 and PO-1 grants.

Finally, Mr. Chairman, I should like to again say that we are all grateful for the attention that this committee has given this year and in the past, and we wish to thank you for your attentiveness.

Senator INOUYE. Thank you very much, Doctor. Like many, I have a thoroctomy scar so that makes me a bit biased. You can be assured of my support.

Does this language help Mrs. Monaco?

Dr. TALBOT. Not directly, although—that is to say yes and no.

There's a lot of work of the sort that she's talking about going on in cancer centers, as you well know. She's talking about a much broader sphere of what I would judge to be more diffuse delivery than that, if I understood her correctly, Senator.

That will require support for the clinical programs that she's speaking about. I can promise you I'm by no means opposed to that. How could I be?

Senator INOUYE. I thank you very much. You better get together with her.

STATEMENT OF JOHN F. WILLIAMS, M.D., PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Senator INOUYE. Our next witness is Dr. John F. Williams, president of the American College of Cardiology.

Welcome, sir.

[The statement follows:]

STATEMENT OF JOHN F. WILLIAMS, JR., M.D.

Mr. Chairman and members of the Subcommittee, I am Dr. John F. Williams, Professor of Medicine and Director of the Cardiology Division at the University of Texas Medical Branch in Galveston. I appear before you today representing the 12,500 member American College of Cardiology (ACC)* of which I am currently President. The College appreciates this opportunity to discuss its concerns relative to the proposed Fiscal Year 1985 budget for the National Heart, Lung, and Blood Institute (NHLBI). Since I have had the privilege of being a research fellow at NHLBI many years ago and have held a number of grants funded by that Institute, it is a personal pleasure for me to be here to talk with some of the individuals who are responsible for making the NIH the great biomedical research institution that it is.

Before commenting on specific NHLBI programs, I would like to place our views in perspective. I need not remind the members of this Subcommittee of the history of the Institute which began with the passage of the National Heart Act in 1948, a time when cardiovascular diseases had reached epidemic proportions. During the ensuing 36 years the Heart Institute grew in size and scope, became the National Heart and Lung Institute and then the National Heart, Lung, and Blood Institute. It now encompases four of the ten leading causes of death: heart disease first; cerebrovascular diseases third, chronic obstructive pulmonary disease fifth and arteriosclerosis ninth.

In view of these enormous responsibilities and the magnitude of the problems the Institute addresses, it is pertinent to evaluate the funding status of the NHLBI relative to the other institutes. In the period from 1979 to 1984 the funding for the Institute was considerably less than that of 7 other institutes, which are smaller in mandate and size. Further, during the last several years, NHLBI has been able to fund fewer approved grants by percentage than any of the major institutes. In FY 1984 only 31.6% of approved grants were funded, while some other institutes were able to fund greater than 40% of approved proposals. Only within the past two years have your appropriations to NHLBI allowed, for the first time in several years, any real growth in the program. We are deeply grateful to the members of this panel for supporting these increases.

---

*The American College of Cardiology (ACC) is a non-profit professional medical society dedicated to ensuring optimal care for persons with or the potential for developing cardiovascular disease, and through education and socioeconomic activities, the prevention of cardiovascular disease.

Our concern for NHLBI funding is heightened further by a review of several statistics:

- 16.5% of this country's population suffers from cardiovascular diseases and two thirds of these individuals are under 65 years of age;
- Cardiovascular diseases account for an estimated 49.6% of the deaths in individuals between the ages of 35 and 74. It is still the leading cause of death of Americans;
- Almost 60 million individuals in the U.S. suffer from hypertension; moreover, 26% of these individuals are unaware of it;
- Compared to other major diseases, cardiovascular disease accounts for the greatest number of deaths as well as short stay hospital days and worker disability allowances;
- In economic terms the cost of heart disease to the nation is staggering -- $97 billion in 1981 for hospital care, physician and other professional services and lost productivity. The amount spent for the care of heart disease alone equals 1% of the nation's gross national product.

These alarming facts are somewhat offset by the enormous advances that have been made in the fight against heart disease since the original creation of the Institute. These include:

- A consistent decline in the annual age-adjusted cardiovascular death rate since 1963. Since 1960, the death rate from cardiovascular disease decreased by 38%, when comparable rates for other diseases fell by only 13%;
- A 29% reduction in mortality rates for coronary disease;
- A 44% decrease in mortality rates for stroke;
- In 1981, cardiovascular disease accounted for less than 50% of all deaths in the U.S., despite a population increasing in both size and age.

The fundamental importance of investment in basic research is heightened by its application in clinical settings. A few examples from recent NHLBI projects are illustrative of the benefits that can accrue to our society from its investments in basic research:

- The Coronary Primary Prevention Trial (CPPT) which was the first study in humans to establish the link between lowering blood cholesterol and a reduction in the incidence of heart attacks and deaths from heart attacks;
- The Coronary Artery Surgical Study (CASS) which is providing physicians with valuable data relative to decisions on whether or when to recommend bypass surgery for individuals suffering from coronary artery disease;
- Key advances in the understanding of the causes and prevention of atherosclerosis which underlies coronary heart disease in most individuals;
- Refinement of newer techniques, such as radioisotope tracers, to diagnose and measure heart muscle damage;
- Therapeutic advances such as balloon dilation of the coronary arteries, a procedure known as "percutaneous transluminal coronary angioplasty (PTCA)," to alleviate coronary obstructions.
- Demonstration of the effectiveness of the workplace as a locus for instituting and maintaining measures for the control of high blood pressure.

Although much has been accomplished in the last 36 years, considerably more needs to be done in the future. Cardiovascular disease continues to pose serious threats to the health and well-being of populations both in the U.S. and the rest of the world.

Given the impact of cardiovascular disease on our citizens, enactment of the Administration's budget proposal for NHLBI, and, indeed NIH as a whole, would result in missed opportunities with the potential for reaping enormous benefits in terms of both health and economics. The Administration's proposed 2.2% increase would be grossly inadequate allowing the Institute to meet only minimal needs. Enactment of the Administration's budget would make possible an award rate of only 26.3% for approved grants -- the second lowest of any institute.

Indeed, enactment of the proposed budget would result in an actual decrease from the number of competing investigator initiated grants -- the bedrock of scientific advances -- the Institute was able to fund this year. Enactment of the proposed budget also would severely hamper the Insititute's prevention, education and training activities which are essential to translating the benefits of basic research into the practice of medicine.

Preliminary data emanating from NHLBI programs strongly suggest that we are on the verge of important findings in a variety of significant areas. Funding above the Administration's request is essential for carrying these forward. Briefly, these include:

- Systolic Hypertension in the Elderly Program (SHEP). This initiative by NHLBI and NIA will assess whether long-term investment with anti-hypertension drugs will reduce the incidence of stroke in elderly subjects with isolated systolic hypertension (ISH). This full scale trial which will start in FY 1984 follows a pilot study on the same subject supported by the NHLBI and NIA from FY 1980-1983. Preliminary results of the pilot study indicate that ISH can be successfully treated and that the elderly would be willing to participate and comply with drug intervention.

- Cardiac Arrhythmia Pilot Study (CAPS). NHLBI is undertaking a pilot study to demonstrate the feasibility of a full scale clinical trial to evaluate the impact of therapy of rhythm disturbance of the heart on mortality, presumably through a reduction in sudden cardiac death.
- Further understanding of the relationship between hypertension and the techniques of neurobiology.
- Further development of new non-invasive diagnostic and therapeutic techniques, such as laser technology and nuclear magnetic resonance imaging systems.

It is our recommendation that the Congress grant NHLBI a 16% increase over FY 1984 to enable the Institute to pursue the wide spectrum of research, prevention, education and training activities that its broad mandate demands.

We feel that given the myraid of opportunities that exist, this is not an unreasonable request and is consistent with both the Administration's request for the research and development budgets and the rationale underlying this request for other Federal scientific agencies: "... the long-term economic strength of the nation and continued improvement in the well-being of its citizens requires a sustained investment in basic scientific research." We strongly believe that the research supported by NHLBI falls well within this justification.

Enactment of the 16% increase would permit NHLBI to maintain its current research effort and would allow expansion into new and promising areas of inquiry. Further, it would permit the Institute to continue its balanced set of programs without reducing one at the expense of another --- which the Administration's budget request would clearly force NHLBI to do.

Finally, I would note that the impact of the Administration's proposal on the number of research trainees NHLBI could support would be particularly regrettable and counterproductive. The number would fall by 211 from FY 1984. Enactment of the recommended increase would encourage physicians to pursue research careers and assure that the United States has an appropriately trained cadre of investigators necessary to maintain our country's world preeminence in biomedical research.

Thank you for the opportunity to discuss these issues. I'd be happy to answer any questions you may have.

Dr. WILLIAMS. I am Dr. John Williams and I'm here today representing the 12,700 physicians and scientists who form the American College of Cardiology of which I currently am president. I greatly appreciate the opportunity to appear here today and to present to you some of our thoughts and concerns regarding the appropriations for the National Heart, Lung, and Blood Institute.

It's a subject which really is quite close to my heart since I received part of my training at the Institute and, for many years, I received research support from that Institute.

We have submitted written testimony and, today, what I'd like to do is merely emphasize aspects of that testimony and to answer any questions that you may have. I know that we don't need to convince the members of this subcommittee of the importance of NHLBI and its programs. You've amply demonstrated your support in the past.

I know, too, that you probably have been told many times of the rather dramatic decline in deaths from cardiovascular disease that have occurred in this country in the last two decades. In great part, that's attributable to the programs, I think, of the National Heart, Lung, and Blood Institute.

Yet today the programs of the Institute really are threatened by budgetary restrictions. The administration has proposed a 2.2-percent increase in appropriations for fiscal 1985.

If the budget increase for the Institute is limited to that degree, it will not only prevent progress in its programs, it will actually result in a decline in two critical elements. One is the number of grants to individuals for research support, and the other is in the training of individuals as cardiovascular scientists.

Unfortunately, the results of such actions are not going to be readily apparent for the results of research activity today really aren't felt for many years. The decline in cardiovascular deaths, to which I alluded a moment ago, really didn't come from any single dramatic development that happened yesterday.

In fact, it resulted from numerous small studies, the results of which probably had no impact on health at that particular time; but they formed the foundations on which that next small advance could be made ultimately leading to what we have seen and the improvement in the care of patients with cardiovascular disorder.

So what we do today and what we can afford to do today really is our health legacy. We believe that an increase in appropriations for the National Heart, Lung, and Blood Institute of 16 percent is necessary if the Institute is to maintain the progress in its current programs in cardiovascular training and in cardiovascular research. In fact it's in keeping with the administration's request for research funding for other Government agencies.

I'm certainly well aware of the great difficulties you all face today when we have large budget deficits in trying to allocate our financial resources. I'm well aware that there are numerous other groups who believe that their needs for increased funding are just as legitimate as ours are.

My purpose in being here today is to provide you with information which I hope will be helpful as you try and reach these tremendously difficult decisions. I would be remiss in my responsibility to you and to the people if we didn't do that; and I appreciate the opportunity to be here today.

Senator INOUYE. Well, I can agree with you even if I'm not a doctor because every time you look at an obituary, it seems to be either cancer, something to do with the lung, the blood or the heart. In fact, we just lost a dear friend, Senator Church, from cancer.

Dr. WILLIAMS. Yes.

Senator INOUYE. Just by coincidence, we've been having one death per month among the men who served with me in my old rifle company during World War II, and it's 50 percent cancer and 50 percent heart attack.

Dr. WILLIAMS. We have made dramatic progress, I think, in reducing mortality. Unfortunately, cardiovascular disease still remains the No. 1 killer in this country. So we have much we need to do and we need the support.

Senator INOUYE. What role does tobacco play in this?

Dr. WILLIAMS. It plays a major role. It seems to be unquestioned that it's a risk factor in the development of heart attacks and certainly in people who have heart attacks who continue to smoke. They are at much more risk than those who can stop smoking. Tobacco plays a role.

Senator INOUYE. What about diet?

Dr. WILLIAMS. Diet? Diet does play a role. The whole problem of cholesterol. The National Heart, Lung, and Blood Institute recently reported on its trial in cholesterol lowering agents which showed for the first time that if you lower cholesterol you really can reduce your chances of having a heart attack; the results of a clinical trial supported by NHLBI. So diet is important in this.

It's a multifactorial problem in which you can't just attack one small aspect. There are many things which probably can create to the development of things.

Senator INOUYE. I realize that no one can give a definite answer to this inquiry, but this is in support of your case.

If the U.S. Government, the Congress, and the administration had provided only half the amount we had provided in the last decade, where do you think we'd be today?

Dr. WILLIAMS. It would be a catastrophy. If we had had only half the money to support only half the programs that currently are undertaken, I think we would be years and years behind.

Again I say, this is a legacy that we have. What we do today is going to affect our children and the people to come. Research is a slow evolving process in which you build things.

So what we do is really for our children today. It may not help you and me, but it's certainly important to them.

Senator INOUYE. Well, you have my vote.

Dr. WILLIAMS. Thank you.

Senator INOUYE. Thank you, sir.

STATEMENT OF JAMES A. SWOMLEY, MANAGING DIRECTOR, AMERICAN LUNG ASSOCIATION

PREPARED STATEMENT

Senator INOUYE. Our next witness is the managing director of the American Lung Association, Mr. James Swomley. Did I pronounce your name correctly?

Mr. SWOMLEY. Yes, you did, sir.

Senator INOUYE. Welcome, sir.

[The statement follows:]

STATEMENT OF JAMES A. SWOMLEY

Thank you very much for the opportunity to put before you the views of the volunteers of the American Lung Association and the scientists and health professionals of the American Thoracic Society, ALA's Medical Section. I am James A. Swomley, Managing Director of the American Lung Association.

First of all, we want to commend the members of this Subcommittee for achieving in fiscal year 1984 the passage and signing of the first regular appropriations bill in five years for Labor, Health and Human Services, Education and Related Agencies. The ALA/ATS wishes you well in passing a similar bill for FY 1985.

The concerns the ALA wants to focus on today are those relative to the prevention and control of lung disease. These diseases constitute a devastating and growing public health problem in the United States (attachment 1). They include lung cancer and emphysema and altogether these diseases rank third among the leading causes of death and sixth among conditions responsible for premature retirement for disability. Respiratory complaints are the reasons for 12% of hospital admissions and for 20% -- 1 out of every 5 -- visits to doctor's offices. COPD - as Chronic Obstructive Pulmonary Diseases such as emphysema, bronchitis and asthma are called -- is among the most rapidly increasing of the 10 leading causes of death. COPD had a 60% rate of increase between 1969 and 1979. The direct and indirect costs of lung diseases are about $45 billion annually.

These respiratory disease trend-lines become particularly sobering when viewed in the context of this country's aging population. The percentage of the U.S. population 65 and over has now topped 11% and is projected to be headed toward more than 15% in the next 10 years. Within that phenomenon is another one -- the "aging" of our aging population. The number of persons in the above-80 category comprises an increasingly large proportion of all persons 65 and over. This trend will have great significance in many respects over the next few decades. For chronic lung disease it means the situation is going to get worse before there is improvement. And for that improvement to occur will require a more substantial commitment of resources than has been the case up to now. The

ALA urges that our public policy call for stepped-up efforts by federal programs that can make a significant difference in our lung health future.

Federal health programs such as those of the National Heart, Lung and Blood Institute give strength and leadership to the entire spectrum of lung disease care, control and prevention in this country. For instance, deaths from neonatal respiratory distress syndrome, a leading cause of death and morbidity among new borns, have fallen steadily as a result of federally sponsored research. There are other examples of the potential for accelerating our inroads on the problem of lung disease if we but commit the resources:

- Basic research on the structure and function of the lung and/or the development of diseases of the air-ways and lung parenchyma continues to disclose the ways in which dust particles and toxic vapors associated with job, home and air pollution cause chemical injury to the lung. This understanding offers new opportunities for treatment and prevention of pulmonary disease in in variety of community and occupational settings -- should major additional funds be available to NIH.

- The knowledge is at hand to mount major new initiatives on COPD which would make it possible to reverse COPD trends in the next decade.

- Similar strategies could be applied to Cystic Fibrosis, the most common chronic fatal respiratory disease of children.

- Exciting opportunities also exist for stepped-up research in human biology and the problems of bronchial asthma, occupational asthma, allergies and related immune disorders.

- Stepped-up surveys on smoking patterns and educational programs that are included in the current federal budgets plus on-going prevalence surveys as proposed in the FY85 budget should permit even more focused educational programs in the future to further reduce the rate of smoking -- long identified as the primary cause of emphysema.

o And as this Subcommittee well knows, modest additional federal resources targeted to select Tuberculosis problem areas provides the critically important addition to health departments of community outreach workers to help contain future TB infection and bring about expedited programs that are highly cost effective.

In regard to this very important last point, the Board of Directors of the American Lung Association has asked me to convey to you, the appreciation of ALA/ATS and all the other concerned public health groups in the country for the sustained funding support you have provided the Tuberculosis program in the CDC budget. The Administration has not requested funding for this special program because it feels block grant funds can do the job but actuality paints a contrary picture. The funds you have made available fill a real local need. For instance, the Miami area TB case rate went down from 87 per 100,000 in 1981 to 64 in 1982. In Los Angeles, the case rate went from 32.5 per 100,000 in 1981 to 25.3 per 100,000 in 1982. The national average for TB cases is about 11 per 100,000.

* * * *

The ALA/ATS each year carefully evaluates the progress and the needs of the NHLBI, the National Institute for Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, NIOSH and the other federal programs of consequence to lung disease. We feel that as far as FY85 is concerned the President's budget, with two modest exceptions, seriously misses the mark. At the very time that Congress has reiterated its commitment to basic biomedical research and other programs of prevention,the Administration recommendations would result in lost momentum in key programs and missed research opportunities. ALA/ATS recommendations for FY85 appropriations which have been unanimously approved by the ALA Board of Directors are described in attachment 2 and are listed in the summary which preceded my testimony. I'll be glad to answer any questions you might have.

ATTACHMENT 1

March 1984

ISSUE BRIEF: MAGNITUDE OF LUNG DISEASE

Overview

Respiratory diseases are a devastating health problem in the United States, ranking third among the leading causes of death and sixth among conditions responsible for premature retirement for disability. Chronic respiratory diseases are the most rapidly increasing of the 10 leading causes of death. That acceleration in mortality has occured during a time when the mortality rate from all causes of death has significantly declined: for example, cardiovascular disease mortality has decresaed 24 percent during the period 1968-1978.

Although the effects on mortality are significant, chronic respiratory diseases tend to have an even greater effect on morbidity and disability. Chronic respiratory disease is the most frequent reason that people seek medical attention, accounting for more than 20 percent of all physicians contacts and 12 percent of all short-term hospital stays. Further, there are more lost workdays from respiratory disorders (31.3 million person-days annually) than from any other category of illness. The direct and indirect costs are a staggering $45 billion annually.

Respiratory diseases constitute an array of conditions of the lungs and the upper respiratory system. Of particular importance are the chronic obstructive pulmonary diseases, asthma, lung cancer, the interstitial pulmonary diseases, tuberculosis and other infections, cystic fibrosis, other pulmonary disorders of special importance in the pediatric population, and pulmonary vascular disease.

Chronic Obstructive Pulmonary Disease (COPD)

Between 1969 and 1978, COPD had the most rapid rate of increase (60 percent) among major causes of death and accounted for 45,000 deaths in 1978. Although COPD death rates have accelerated rapidly in all sex/race categories, the increase in white females is of special concern. Between 1968 and 1978, age-adjusted COPD mortality had increased threefold.

Prevalence estimates of COPD tend to underestimate the magnitude of reported conditions of emphysema, chronic bronchitis, and asthma. On the basis of a probability sampling of U.S. households, it is estimated that 16 million Americans are affected by one or more forms of COPD. The prevalence of asthma has remained relatively constant but is believed to affect 5 percent of the population. However, during the past 10 years, the prevalence of emphysema increased 58 percent, whereas chronic bronchitis increased 12 percent.

In 1980, there were 998,000 hospital discharges for COPD and allied conditions. The economic effect of COPD is extensive. Costs related to hospitalization and continuing care of patients with COPD are in the neighborhood of $3.8 billion annually, whereas treatment costs approximately $1.0 billion.

Lung Cancer

In 1982, 110,000 American deaths will be certified as caused by lung cancer, and more than 120,000 cases of lung cancer will be newly diagnosed.

The mortality rate of lung cancer has undergone a precipitous (280 percent) increase over the past 30 years. Projections of lung cancer mortality over the next decade indicate a 28 percent increase in males and an 84 percent increase in females, based on applying the annual rates of increase to lung cancer between 1970 and 1975 to the period 1980-1990. Thus, projected rate of increase of lung cancer in women is of special significance. It has been predicted that lung cancer will supersede breast cancer as a cause of death in women during the next decade.

Pediatric Lung Diseases

Asthma, cystic fibrosis, respiratory distress syndrome, bronchiolitis, and other respiratory infections constitute a significant source of morbidity and disability in the pediatric population.

- o **Asthma** affects 2 million children under the age of 17 and is a major source of school absenteeism and unplanned medical interventions. More than 3.6 million physician visits are made annually for medical consultations related to asthma and its complications.

- o **Neonatal Respiratory Distress Syndrome (NRDS)** is the most significant cause of neonatal mortality in the United States. NRDS accounts for 20 percent of total mortality experienced in the first year of life. The average cost for treatment and continuing care of the infant with NRDS is conservatively estimated to be $5,000. Each year 50,000 infants are affected by NRDS, leading to direct costs in the neighborhood of $250 million. As greater numbers of infants with NRDS are surviving, the prevalence of the disabling sequelae from NRDS is placing an increasing burden on the medical systems that provide continuing care and rehabilitation for those children.

- o **Bronchiolitis** is an obstructive respiratory disease of infancy and childhood, usually caused by infection with respiratory syncytial virus. Although generally of short duration, the inflamation of the bronchioles may affect subsequent lung development and have adverse consequences later in life. In 1980, 3,075,000 children under the age of 6 years were affected by acute respiratory illnesses, including bronchoiolitis and pneumonia.

Tuberculosis

In 1980, 28,000 newly diagnosed cases of tuberculosis (TB) were reported in America. During the past 25 years, the number of reported TB cases has declined by approximately 4 percent a year. However, the incidence of TB in 1980 represented a 0.6 percent increase over that reported in 1979, such a consecutive increase in the TB case rate has occurred only twice during the past 25 years. A major contributing factor for the increase in incidence in 1980 was the large number of TB cases diagnosed in the Indochinese refugee population migrating to the United States during 1979 and 1980.

In 1981 the rate declined 6 percent to 27,373 cases and in 1982 a furhter decline of 7 percent to 25,522 was noted. This decrease represents the anticipated decline with adequately functioning TB control programs.

TB in children under 15 continues to present a public health problem. The incidence rate in children has shown no decline in the period 1976-82.

ATTACHMENT 2

March 1984

FACT SHEET: FY85 APPROPRIATIONS RECOMMENDATIONS

The federal government programs give strength and leadership to our entire health care system. The ALA/ATS have evaluated the budget needs for the National Heart, Lung and Blood Institute and its Division of Lung Disease, as well as other Institutes and agencies responsible for lung-related research, training, prevention and education. We are deeply concerned that earlier unrealistic budgets will cost more in the long run than any supposed short-term savings. Our concern is for missed research opportunities and dismantled programs which will cause lost momentum in key areas. We urge restoration of adequate budgets to these programs returning them to a level of national priority.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE / FY85 RECOMMENDATION $788 MILLION

Basic research on the structure and function of the lung and on the development of diseases of the airways and lung parenchyma continues to disclose the ways in which dust particles and toxic vapors associated with job, home and air pollution cause chemical injury to the lung. This understanding offers new opportunities for treatment and prevention of pulmonary diseases and control of the costly and debilitating effects of chronic bronchitis, asthma, emphysema, pulmonary fibrosis, and pulmonary vascular diseases.

The ALA/ATS strongly supports continuation of the Specialized Centers of Research in Adult Respiratory Failure. The goal of this program is to foster a concerted research effort that involves basic scientific disciplines that will solve the clinical problems encountered in the acute respiratory failure. The objective of the research program is to improve the diagnosis, management, and prevention of Adult Respiratory Failure. Such a coordinated approach to lung disease is cost effective in getting to ultimate solutions.

The knowledge is at hand to mount a sorely needed attack on chronic obstructive lung diseases (COPD), now the fifth cause of death in the U.S. Such an offensive would make it possible to reverse COPD trends in the next decade. This type of initiative will only be possible with substantial increases in the NHLBI budget that will allow for real growth on a consistent basis.

NATIONAL INSTITUTE FOR ALLERGY AND INFECTIOUS DISEASES / FY85 RECOMMENDATION $345 MILLION

The research responsibilities of NIAID include a number of respiratory disorders, such as tuberculosis, asthma, influenzas and pneumonias and a host of other bacterial, viral and immunologic diseases that affect the lung. It was NIAID whose support led to an effective vaccine against pneumococcal pneumonia. NIAID-supported studies have identified opportunities for increased research in human biology. These studies covered bronichial asthma, problems of allergic children, drug allergy, occupational asthma, and related immune disorders.

NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES / FY85 RECOMMENDATION $196 MILLION

A significant portion of the work of this Institute relates to pulmonary health. The completion of new research facilities has allowed the expansion of most intramural research including the efforts of the Laboratories of Pulmonary Function and Toxicology and Pharmacology. Important research being conducted includes studies in environmental carcinogenisis and the lung, and inhalation studies of various compounds to identify pulmonary toxicity. NIEHS has been given the lead role in the National Toxicology Program and is working closely with the National Institute for Occupational Safety and Health to set up a practical system to identify and evaluate multitudinous chemical hazards.

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH / FY85 RECOMMENDATION $79.4 MILLION

This Institute has a primary role in national efforts to protect the work force from hazards through the development of workplace standards for exposure to hazardous substances. Much of the Institute's work at the Appalachian Laboratory is devoted to respiratory disease and how it develops as a result of occupational exposure. A vital part of the NIOSH program are the Educational Resource Centers which are responsible for a key portion of manpower development in the prevention and control of occupational lung disease and other related diseases in the workplace. We recommend that funding in the amount of $16.5 million be earmarked for the ERC's.

PEDIATRIC PULMONARY CENTERS / FY85 RECOMMENDATION $4 MILLION

Pediatric Pulmonary Centers are currently funded through the Maternal and Child Health Block Grant and function as referral centers for the expert diagnosis and treatment of pediatric pulmonary problems. Many of the children admitted have asthma or cystic fibrosis--some are infants with life-threatening respiratory problems. The centers also provide training opportunities in pulmonary disease for medical and paramedical personnel.

TUBERCULOSIS PROJECT GRANTS / FY85 RECOMMENDATIONS $12 MILLION

Tuberculosis Project Grants are administered through the Centers for Disease Control. Congress is moving to reauthorize this program in recognition that a special step has to be taken in order to assure getting limited federal funds to targeted high incidence areas. TB is a major public health concern particularly in large cities and areas that have experienced a significant refugee influx. TB is medically treatable and the continuation of efforts to curb its growth could lead to its ultimate eradication.

OFFICE ON SMOKING AND HEALTH / FY85 RECOMMENDATION $4 MILLION

This office was established to serve as the focal point for all DHHS smoking and health activities. In addition to preparing the annual Surgeon General's Report on the Health Consequences of Smoking, this office is responsible for increasing and refining the scientific data base, developing national public information and education programs and serving as one of four World Health Organization Centers on smoking and health.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION / FY85 RECOMMENDATION $4.5 MILLION

The mission of this office is to help promote health and prevent disease among Americans. The focus of activity is on achieving the 1990 Prevention Objectives identified in Healthy People: The Surgeon General's Report on Health and Disease Prevention including smoking prevention, toxic agent control and occupational safety and health.

Mr. Swomley. Thank you very much, Mr. Chairman. We are indeed appreciative of the opportunity to appear here before you today and it is my privilege to testify for the American Lung Association and for its medical section, the American Thoracic Society which includes 8,500 physicians and scientists worldwide who are concerned with lung disease.

We have gone through a laborsome process in preparing our recommendations as an association for consideration by this committee. We have given our attention to nine programs that you fund or consider through this particular committee because we feel that these nine programs are extremely important to the lung health of the American people.

I should say in this regard that the estimated cost of lung disease in the United States at the present time is $45 billion per year. Unlike many disease entities, we find that a number of the lung diseases are increasing rapidly in our society.

When we lump together the various diseases of the lung, we find that we have the third leading cause of death.

Of particular concern to us is chronic obstructive pulmonary disease and we have noted that there has been a 60-percent increase in mortality from chronic obstructive pulmonary disease in the last 10 years.

Senator Inouye. What type of disease is that?

Mr. Swomley. Emphysema, chronic bronchitis, other diseases that impair the breathing capabilities of an individual. Some of these relate to smoking. In fact, smoking is probably the biggest single factor, but there are genetic factors, there are occupational health factors, there are many other considerations here.

When we talk about what can be done about these problems we give very high marks to the National Heart, Lung, and Blood Institute. We feel that we have, in that Institute, a very dedicated staff that is providing outstanding leadership and that here is a real potential for doing something about this problem in the future.

I can't help but be impressed as a layman who works with leading scientists around the world in this particular area with the tremendous enthusiasm that they have for the potential of research to do something about this problem.

I must say that I have always been something of a skeptic, but as I see and work with these men and women and just see the opportunities that they visualize and the importance of funding this particular Institute at a level that's going to not only maintain but improve our capabilities for research, I am most impressed.

Two other areas that I might call attention to out of the nine that are in the testimony that we are filing with the committee. One pertains to tuberculosis and I understand that you, in Hawaii, have had some interest in this particular project and I know that our director in Hawaii, Don Ford, has had an opportunity to work with your office and very much appreciates the work that you have done over the years on behalf of prevention and control of lung disease.

Senator INOUYE. We have an overabundance of refugees, as you know——

Mr. SWOMLEY. Yes.

Senator INOUYE [continuing]. Coming in from the Pacific areas.

Mr. SWOMLEY. This is why I would like to emphasize today our belief that the tuberculosis project grant funds should continue. The administration has looked toward block grants, but we feel that there are certain areas, such as tuberculosis, where project grants are important; one being the refugee problem that you mentioned.

Another being the fact that we have somehow in this country failed dismally in making further inroads on the infection rate in children.

If we go back to 1904 when the American Lung Association began as the National Tuberculosis Association, when tuberculosis was the leading cause of death in this country, and look at the progress from then until now we find, had the death rates of 1904 continued we would have 17 million additional deaths from tuberculosis over this span of time. So what has been accomplished is truly miraculous, but it is unfortunate that pockets of TB continue when we should be able to wipe it out; and that's why we put the emphasis on the project grants for tuberculosis.

If I may take just a few seconds more, I would also like to emphasize the importance of the very, very modest budget of the Office of Smoking and Health. Smoking is claiming 340,000 American lives each year and the Government is spending very little on the prevention aspects of this program.

We hope that this program can be enhanced because it's going to mean a great deal to the future of this country. When we see that money is spent to fund the administration for the Tobacco Subsidy Program, that we're probably going to have tremendous costs for tobacco that is literally spoiling in barns around the country, we think it's important that we have the same commitment to prevention that we do to this problem.

Senator INOUYE. Do you think $4 million is enough for POASH?

Mr. SWOMLEY. The recommendation is worked over rather carefully by our committee. Personally, I think it's a small amount, but it does provide for growth from a year ago.

Senator INOUYE. I have been told by every witness that tobacco is a major concern, in fact a major cause of problems of the lung.

Mr. SWOMLEY. Yes.

Senator INOUYE. Yet here we find $4 million for the Office of Smoking and Health, and $3.5 million for prevention.

Mr. SWOMLEY. We do have our priorities, in many respects, out of order in this country.

Senator INOUYE. So you would be in favor of greater emphasis in these two areas?

Mr. SWOMLEY. I personally would be in favor of greater emphasis. The figures I have for you here I guess represent what our committee felt would provide for a modest growth that we might be able to urge the committee to accept.

I certainly would not oppose a further increase in those funds. I think it would be most helpful.

Senator INOUYE. Sometimes we are not too impressed with $1 million. Apparently, in this Government, every time you sneeze we spend about $10 million. So $4 million isn't much.

Mr. SWOMLEY. Right.

Senator INOUYE. I thank you very much, sir.

Mr. SWOMLEY. Thank you, sir.

STATEMENT OF PAUL R. McCURDY, M.D., CHAIRMAN, PUBLIC EDUCATION COMMITTEE, AMERICAN SOCIETY OF HEMATOLOGY

PREPARED STATEMENT

Senator INOUYE. Our next witness is the chairman of the public education committee of the American Society of Hematology, Dr. Paul R. McCurdy. Dr. McCurdy, welcome, sir.

[The statement follows:]

STATEMENT OF PAUL R. MCCURDY, M.D.

At the start, I wish to thank you for the opportunity to present testimony before this Subcommittee in connection with the legislation for the Fiscal Year 1985 appropriations for the National Institutes of Health.

I am Dr. Paul R. McCurdy, Director of the Washington Region of the American Red Cross Blood Services and Professor of Medicine at Georgetown University School of Medicine. I am also Chairman of the Public Education Committee of the American Society of Hematology. This society has more than 3,000 members and is the only national organization of hematologists and is made up of physicians and biomedical scientists who are concerned with research, patient care and teaching as they relate to blood.

Before presenting my views about this legislation, I would like to express our deep gratitude to you, Senator Weicker, to your associates on this committee and to the entire Congress for their strong support last year on behalf of biomedical research and hematology. We greatly appreciate your long-standing commitment to the programs of the National Institutes of Health.

Blood and bone marrow are easy to obtain for study; hematology, both at the bedside and in the laboratory, has lent itself to quantitative technics almost from its beginning as a science. Blood affects and is affected by diseases of many organs and systems. Consequently, hematological research has been very productive, both as to the treatment of disease and toward the development of basic biomedical scientific knowledge applicable across much of medicine. For example, pernicious anemia, once thought to be a form of blood cancer, is now easily treated with vitamin B-12 as a result of a classic series of clinical and laboratory studies. Many children with acute leukemia now have prolonged remissions off treatment and may be cured. Single building-block changes in proteins, first described for sickle hemoglobin, are now known to be responsible for a large amount of person-to-person variability and for many diseases, such as other abnormal hemoglobins, enzymes in red cells and other tissues, membrane proteins, etc. The cracking of the genetic code was significantly aided by studies of abnormal hemoglobins. I have been privileged to be a small part of some of these advances and would like to have you feel at least a bit of the excitement I have had as a result.

Studies aimed at detecting the primary abnormality in Cooley's anemia, or thalassemia, led to a detailed understanding of protein synthesis. Information as to the role of RNA and DNA led via multiple paths to prenatal diagnostic technics for this and other disorders, to the use of DNA analysis as a simpler and quicker way to unravel protein structure than examination of the protein itself, and even to much of the genetic engineering excitement of today. Most of these studies were done by investigators asking fundamental non-targeted questions. Better understanding of the abnormalities of Cooley's anemia and some of the results of an ineffectively hyperactive bone marrow led to hypertransfusion therapy with great benefits in well-being and quality of life for these children. The excessive iron they accumulate from many blood transfusions is treatable with the expensive "orphan drug", desferrioxamine, although more research is needed on the best way to use this drug and the results to be expected. From hematology has also come basic research into the way genes are turned on and off — for example fetal hemoglobin synthesis, normal during gestation, is slowly switched off and the production of normal adult hemoglobin commensurately turned on at about the time of birth. Recently, serendipity and prepared scientific minds have found another 'orphan drug' that seems to switch fetal hemoglobin production back on. This drug shows promise for the treatment of both Cooley's anemia and sickle cell anemia, but much research is needed before we can comfortably recommend it as appropriate therapy. In the meantime, bone marrow transplantation, developed as treatment for aplastic anemia and later acute leukemias, has been successfully applied as therapy for Cooley's anemia. A sickle cell patient, given a bone marrow transplant as part of therapy for leukemia, now shows no evidence of sickle cell disease. Bone marrow transplants for various indications are almost as commonly done as kidney transplants.

Blood transfusions, so important to the life and well-being of patients with thalassemia and other chronic anemias, so important to the survival of many trauma victims, and so important to the ability to perform many modern complex and life-saving surgical procedures, have been known for years to have unwanted effects, like all potent forms of therapy. Recent advances have led to better preservation of red cells and platelets, extending their shelf life and minimizing loss from outdating. A surprise discovery by an investigator looking for something else now permits us to test all units of blood for hepatitis B and adds measurably to the safety of blood transfusion. The potential for rapid increase in knowledge in the field of blood transfusion and immunohematology has led the NHLBI to begin a program for Specialized Centers of Research in blood transfusion, a program I believe will be as productive as has been the rest of the SCOR program.

Lymphocytes in the blood demonstrate the major fundamental abnormalities in patients with AIDS. Earlier and on-going research on these cells, begun before AIDS was recognized, has made it easier and quicker to understand some of the basic aspects of this devastating disorder. I am confident that the mystery of this disorder will be unraveled and with it biomedical science will be significantly advanced.

From the above, I wish to make several points: 1) Investigator originated research may seem untargeted and sometimes of questionable merit but such studies are often the most productive. The oft-cited number of 5,000 new and competing investigator instigated grants to be funded each year by the NIH should be regarded as a floor, not as a ceiling nor as a target beyond which we should not aspire. 2) Much of biomedical research is interrelated among overlapping fields. There is a great deal of cross-over of concepts and basic discoveries. 3) Hematology has been and will be a very productive field for research. Like the blood itself, it pervades all branches of biomedical science. Accordingly, hematology research should continue to be supported by multiple Institutes at the National Institutes of Health.

Few of the above advances could have been made without properly trained clinical investigators. The essence of clinical investigation is to take problems from the patient's bedside to the laboratory. Proper training helps one formulate testable hypotheses and determine or devise technics and procedures to test them. Research training should continue to be supported through the dual mechanism of training grants and fellowship awards. Both are productive; neither has been shown to be superior to the other. The decline in MD research scientists and the increase in PhD's in such positions has been of some concern. This is not because PhD scientists are less worthy, but because the commingling in the research atmosphere of clinical problems with research problems will continue to lead to productive approaches to solving the medical care problems that concern us most. I ask that you continue to support research training through the NIH and that means be sought to encourage young promising MD-investigators. Recently, an NIH Committee has reported a serious lag of research trainee stipends behind those given to physicians in clinical training. This "unacceptable discrepancy" may have compelled some potentially talented investigators to choose the clinic over the research laboratory on economic grounds. The relatively small additional sum of $33.4 million will increase both pre-doctoral and post-doctoral stipends to a competitive level without decreasing the number in training.

My recommendations to the Appropriations Committee of the United States Senate are:

1. for the National Heart Lung and Blood Institute, a level of funding of at least $815 million for fiscal year 1985;

2. for the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, a level of funding of at least $550 million for fiscal year 1985;

3. for the National Cancer Institute, a level of funding of at least $1.3 billion for fiscal year 1985;

4. for the National Institutes of Health, a level of funding of at least $5.213 billion for fiscal year 1985;

5. "bill report language" which stresses the fact that blood research is carried out in many NIH Institutes, and particularly in NHLBI, NCI, and NIADDK, and that wide-ranging research effort is recognized and should continue. (We are particularly concerned about the concept of moving all blood research into one institute to "clean up" the NIH organizational system. Of course, as is indicated above, there are valid scientific reasons for blood research to be carried out in numerous institutes.)

6. "bill report language" indicating that the 15% set-aside, originally authorized for blood research when "Blood" was added to the name of the NHLBI (a similar set-aside was provided for lung research in that institute), should be treated as a "floor" and not as a "ceiling."

Dr. McCurdy. Thank you, Senator. Thank you for the opportunity to present testimony before this subcommittee in connection with the legislation for fiscal 1985 appropriations for the National Institutes of Health.

I am Dr. Paul R. McCurdy, director of the Washington region of the American Red Cross blood services and professor of medicine at Georgetown School of Medicine. I am here, however, as chairman of the public education committee of the American Society of Hematology.

This society has more than 3,000 members; is the only national organization of hematologists; and is made up of physicians and biomedical scientists who are concerned with research, patient care, and teaching as they relate to the blood.

Before presenting my views about this legislation, I would like to express my deep gratitude to you, Senator, to your associates on this committee, and to the entire Congress for their strong support last year on behalf of biomedical research in hematology. Your longstanding and obviously continuing commitment to the programs of the National Institutes of Health is greatly appreciated.

Blood and bone marrow are easy to obtain for study. Hematology, both at the bedside and in the laboratory, has always lent itself to quantitative techniques. Blood effects and is affected by diseases of many organs and systems.

Consequently, hematologic research has been very productive both as to treatment of disease and toward the development of basic biomedical scientific knowledge applicable across much of medicine. For example, single building block changes in proteins first described in sickle hemoglobin are now known to be responsible for a large amount of variability and disease. The cracking of the genetic code was greatly facilitated by studies of these abnormal hemoglobins.

Much of our modern work with genetic engineering stems from early work on these abnormal hemoglobins and particularly thalassemia or Cooley's anemia. I have been privileged to be a small part of some of these advances and would like to have you feel at least some of the excitement I've had as a result.

What of now in the future? Better understanding of Cooley's anemia led to hypertransfusion therapy with great benefits in the quality and length of life. This larger number of transfusions led to chronic iron excess, now treatable with a new orphan drug, desferrioxamine. However, additional research is needed to optimize its use and perhaps develop new drugs.

Bone marrow transplantation, developed for treating aplastic anemia, has been successfully applied to Cooley's anemia as well as to many other disorders. More research is needed to improve further marrow transplantation, now the second most common living tissue transplant after kidney.

Senator Inouye. What is Cooley's anemia?

Dr. McCurdy. Cooley's anemia is a hereditary disorder where there is insufficient manufacture of hemoglobin and, in its more severe form, we call it homozygous. It's inherited from both parents. It is transfusion dependent.

I believe you will hear from a member of the Cooley's Foundation, a representative of them, shortly. They may be interested in describing it further.

The first specialized centers of research in transfusion medicine are scheduled to be established soon. This field, somewhat neglected in the past, is ripe for exploitation with new technology and knowledge.

Most of the discoveries noted above and many, many others were made with the support of investigative initiated grants or RO–1's, PO–1's about which you've heard earlier today. Although they may seem untargetted and sometimes of questionable merit, they are often the most productive.

I am mindful of the need for financial constraints, but concerned that sufficient funds be granted not only to maintain funding in real dollars but also to provide the ability to follow new leads or diseases.

We recommend to the Appropriations Committee of the U.S. Senate the following: For the National Heart, Lung, and Blood Institute, a level of funding of at least $815 million for fiscal year 1985; for the National Institutes of Arthritis, Diabetes, Digestive and Kidney Diseases, a level of funding of at least $550 million; for the National Institutes of Health as a whole a level of funding of at least $5.213 billion for fiscal year 1985; and finally bill report language which stresses the fact that blood research is carried out in many of the institutes of the NIH, particular NHLBI, NCI, and NIADDK, and that this wideranging research effort is recognized and should continue.

I'd be pleased to answer any questions that you may have. Thank you.

Senator Inouye. Thank you very much, sir.

How far have we gone in treatment of leukemia in your studies?

Dr. McCurdy. Well, leukemia is not my field. My field has been more genetics and the abnormal hemoglobins; but you've heard earlier today that childhood leukemia is treatable; remissions occur 90 percent or better of the time; and long-term remissions or perhaps cures, 50 percent or more, 50 to 80 percent of the time.

Adult leukemia, uniformly fatal when I was in medical school, now 20, 30 percent or more go into long-term remission.

Senator Inouye. I notice every so often a frantic plea from all of the blood centers because of the lack of blood. Is the time coming when we will be able to develop, say, artificial blood?

Dr. McCurdy. I feel confident that sooner or later we'll develop other ways of obtaining blood than from donors, but very likely this will not happen in my professional lifetime. We will need donors for at least the next 10 or 15 years for red cells and platelets, I'm quite certain.

The genetic engineering I mentioned probably within 5 or 20 years will provide plasma proteins, like maybe hemaphylic factor and so forth.

Senator INOUYE. Can you contribute anything to the ongoing discussion on AIDS and blood centers?

Dr. MCCURDY. It's a very difficult problem. There were measures put in place a bit over 1 year ago, which we are confident will reduce, perhaps not eliminate, the risk of AIDS from blood transfusion. Unfortunately, with the long incubation period, it will be a while longer before we know for sure.

There is a great deal of research, much of which I'm superficially familiar with, sponsored by the NIH and the CDC and other agencies attempting to find the cause, cure, treatment, prevention.

Senator INOUYE. Well, I thank you very much, Doctor.

Dr. MCCURDY. Thank you.

Senator INOUYE. We appreciate it.

STATEMENT OF LEON W. HOYER, M.D., CHAIRMAN, MEDICAL AND SCIENTIFIC ADVISORY COUNCIL, THE NATIONAL HEMOPHILIA FOUNDATION

PREPARED STATEMENT

Senator INOUYE. Our next witness is the chairman of the Medical and Scientific Advisory Council of the National Hemophilia Foundation, Dr. Leon W. Hoyer. Dr. Hoyer, welcome, sir.

We will insert your prepared statement in the record.

[The statement follows:]

Statement of Leon W. Hoyer, M.D.

I am Dr. Leon W. Hoyer. I am Professor of Medicine at the University of Connecticut Health Center, and I am speaking to you today as a representative of The National Hemophilia Foundation as Chairman of their Medical and Scientific Advisory Council.

The Foundation is most grateful for the support that the federal government has provided over the years for much needed hemophilia research and care. As you are aware, this support has hastened and facilitated a revolution in hemophilia treatment over the last ten years. Plasma clotting factor concentrates have become widely available and home infusion therapy has freed these patients from hospital care and emergency room visits. There is no better example of the rapid translation of scientific advances into patient care. The federal and state support of comprehensive care centers throughout the country has provided an essential mechanism for the dissemination of these scientific advances.

A brief review of previous support for comprehensive hemophilia treatment and for hemophilia research will illustrate the progress that has been made.

COMPREHENSIVE CENTERS

In 1975, Congress established the comprehensive hemophilia diagnosis and treatment center program, providing direct federal funding to support the development of 22 comprehensive hemophilia centers and 60 affiliates (Section 1131 of P.L. 94–63). Under the leadership of Dr. Merle McPherson of the Division of Maternal and Child Health, the network of centers has expanded and it now provides a strong regional structure. Over 9500 hemophiliacs (nearly 50% of the total hemophilia population) are now served by these centers. They provide multidisciplinary diagnostic and treatment services including psychosocial, financial and vocational counselling, as well as medical, dental and orthopedic care.

The impact of these programs has been dramatic. Between 1975 and 1981[1]:

- the number of patients seen at both primary treatment and affiliate center sites increased more than 225%;
- the number of patients in these regions receiving comprehensive care and the number on home care has nearly quadrupled;
- this has led to substantial reduction in need for hospitalization so that the average number of hospital days per year per patient has been reduced by 80%; from 9.4 to 1.8;
- moreover, there has been a 75% reduction in the number of days lost from work or school each year; and
- in these difficult times, the percent of unemployed adults dropped from 36% to 12.8% overall – and is as low as 4.5% in some regions, including that which includes the New England states.

---

[1] Collection of comparable data for 1983 is near completion; and will be forwarded to the Subcommittee before April 1984.

These important human benefits have been accomplished by a program that has also led to significant economic savings. Careful studies have documented a 62% reduction in total health costs per patient ($15,800 per year in 1975; $5,932 per year in 1981) for the 9,500 hemophiliacs enrolled in the federally subsidized comprehensive care centers (Maternal and Child Health, Technical Information Series, November, 1982, page 4). This represents an annual savings of $93.7 million — a savings that was achieved by a program that cost the federal government $2.6 million during FY 83. The $2.6 million federal support amounts to $274 per year per enrolled patient and there is an associated $9,868 saving each year that is due to this support. There is no mystery as to how these savings are achieved – comprehensive care prevents complications of hemophilia that require costly hospitalizations[2]. In addition, comprehensive care prepares patients for home therapy so that patients do not need 25–40 hospital visits each year for bleeding episodes. Federal support has made comprehensive care possible for approximately half of the hemophiliacs in this country; I urge you to consider the additional savings that may be realized if increased funding permits comprehensive care programs for the thousands of hemophiliacs not currently enrolled.

Thus: Congress' investment in comprehensive care programs which promote home infusion therapy has paid off by reducing disability, unemployment and the cost of medical care for hemophilic patients.

THE FUTURE OF HEMOPHILIA TREATMENT CENTERS

Three years ago, hemophilia treatment center funding was included in the Maternal and Child Health block grant as part of a special 15% set-aside of appropriated funds. At that time, federal support of the treatment centers was $3.3 million. During the present fiscal year, the funding level is $2.6 million, a 21% decrease. A $300,000 increase is scheduled for the year beginning October 1, 1984. We are grateful that you supported this increase after you considered the needs we presented last year. This has allowed present programs to be maintained, but we are concerned that there are still 25 states that are not entirely covered by the regional federal treatment center network.

On November 28, 1983, an ad hoc Advisory Panel to the Division of Maternal and Child Health Hemophilia Centers Program was convened in Rockville, Maryland to develop a series of recommendations concerning future directions of this program. The report of this panel documented the need for increased funding support to maintain these centers, the importance of expanding psychosocial services, improving coverage to underserved areas through regionalization, improving third party reimbursement for the treatment of hemophilia, as well as identifying 11 areas requiring targeted special efforts. I will gladly provide copies of this six-page report to members of this Committee.

---

[2] A thorough discussion of the cost effectiveness of comprehensive care is provided in "The Benefits of Comprehensive Care of Hemophilia: A Five-Year Study of Outcomes" by Peter S. Smith, M.D., and Peter H. Levine, M.D. This article will be published in the August or September 1984 issue of the American Journal of Public Health.

AIDS: A SERIOUS PROBLEM THAT MAKES THE COMPREHENSIVE TREATMENT CENTERS EVEN MORE ESSENTIAL

Your Committee has heard much testimony about AIDS over the past two years. Of special concern to The National Hemophilia Foundation is that since July of 1982, there have been 30 cases of AIDS reported among hemophiliacs (both children and adults). Of these individuals, none of whom belong to any other risk group, 19 have died.

The recognition that AIDS appears to be transmitted through blood products and clotting factor concentrates has had a profound effect on hemophiliacs and their families throughout the country. The source of their newly-found freedom from pain and disability changed overnight to a possible threat to their very survival. The progress of two decades suddenly became a "mixed blessing." This crisis has created a need for comprehensive care that is greater than ever before. An informal sampling has revealed a 25% to 35% increase in patient encounters at many comprehensive care centers and this is specifically due to concern about AIDS. Physicians and nurses are seeing patients much more frequently and the need for psychosocial intervention has greatly increased. No longer are flu symptoms or fever passed off as trivial problems. The specter of AIDS, a fatal disease that has already been diagnosed in nearly one of every 300 severe hemophiliacs, has had a profound impact on every hemophiliac and his family. This incidence is higher than any other group identified as being at high risk for contracting AIDS. It is obvious that comprehensive care is now even more essential for the entire hemophilia community.

AIDS: WHAT MUST BE DONE

Despite the growing incidence of AIDS, its cause is not known and there are no accepted approaches to its control. As an obligatory recipient of blood products that have the potential for AIDS transmission, the hemophiliac has a special interest in efforts to understand and control AIDS. The National Hemophilia Foundation considers research in this area to be a matter of highest priority and we urge you to give this problem your most serious consideration. The recognition during the past year that AIDS can be transmitted through blood transfusions, albeit very infrequently, emphasizes the widespread public health implications of this disease.

APPROPRIATIONS REQUEST

The issues that I have addressed can be translated into the following requests for appropriations:

1. FY85 Appropriations For Treatment Centers

   We urge you to appropriate $4.6 million for FY85 to support the Hemophilia Treatment Center Program. While this is a $1.7 million increase over the current funding level, it is essential if we are to adequately address the needs of patients not now within the regional comprehensive care programs established by the Division of Maternal and Child Health. The demands on these centers have increased with the AIDS concern and we must respond to this real medical threat. The response requires funding support.

2. Set-Aside

We request that you retain the 15% level for a set-aside within the Maternal and Child Health appropriations. The set-aside was established for a very good reason — it is more efficient to distribute resources for certain disorders on a regional and national basis rather than through block grants to states. The Hemophilia Treatment Center Program is clearly a special program of regional and natonal significance and is a model for other chronic diseases.

3. Maternal and Child Health Funding

We urge you fund Maternal and Child Health at the full authorization level. This funding is an investment in the future of our country.

4. Research

The success of comprehensive care and home infusion therapy might suggest that the "hemophilia problem" has been solved. Nothing could be further from the truth. When CDC announced in July of 1982 that 3 hemophiliacs had contracted AIDS, it was again realized that as long as hemophiliacs depend upon a factor derived from human blood plasma, they will be vulnerable to anything that may contaminate blood products. In addition, clotting factor resistance develops in over 10% of hemophilic patients and these antibodies seriously compromise subsequent care. For these reasons, we are vitally concerned that there be adequate funding for basic biomedical research supported by the National Institutes of Health, and especially the blood diseases and resources research program of the National Heart, Lung and Blood Institute.

We are grateful for Congressional support for increased AIDS related research. Continued and increased funding is needed in this are. The National Institutes of Health, including the National Cancer Institute, The National Institute of Allergy and Infectious Diseases, and The National Heart, Lung and Blood Institute must receive sufficient funding to support a multifaceted research effort that will lead to understanding and control of this disease.

Additionally, the Centers for Disease Control need increased funding so that they can expand their laboratory investigations and epidemiologic studies. We are following very closely the CDC efforts to identify laboratory tests that may be able to detect individuals at high risk of AIDS transmission. This investigation — as part of a broad approach to the AIDS problem — needs full support if we are to reduce the potential risk of AIDS transmission through blood products.

SUMMARY

The concerns of The National Hemophilia Foundation are not different today from our testimony of one year ago. We recognize that only half of the goal of comprehensive care has been obtained at a time when federal commitments are becoming more difficult to maintain. We also recognize that AIDS threatens the gains that have been obtained through joint efforts over the past decade. We need your help to respond to these important problems.

Dr. HOYER. Senator Inouye, my name is Leon Hoyer and I'm professor of medicine at the University of Connecticut Health Center. It's my pleasure to address the committee on behalf of the National Hemophilia Foundation.

Hemophilia is the most common inherited bleeding disorder. It causes disability and early death because of a deficiency of a critical blood protein.

As I and others have testified before, there has been a revolution in the treatment of hemophilia over the past 15 years. It has permitted more effective treatment of these patients through regular transfusion of the missing coagulation factor.

The supervised use of this coagulation factor concentrates through 82 centers supported by the Federal Comprehensive Hemophilia Diagnosis and Treatment Center Program, it has dramatically changed the life of many hemophiliacs.

My written statement documents the progress made through this program. It emphasizes that the improvement and the quality and length of life for hemophilia patients has been associated with economic savings.

It is estimated that this program, funded at less than $4 million per year between 1975 and 1981—the year for which we have most recent figures—reduced the yearly cost of hemophilia care for these patients by over $90 million. This was done by reducing the average expenditure per patient from over $19,000 to $9,000 per year.

There is no mystery in how these savings were achieved. Comprehensive care prevents hemophilia complications, complications that require cost hospitalization. Moreover it enables patients to be treated at home by their infusion of concentrates and avoids costly inefficient emergency room or hospital clinic visits.

These comprehensive care programs are not available for approximately one-half of the hemophiliacs in this country. We urge the Congress to maintain and extend these programs so that the other 9,000 hemophiliacs can obtain comparable care.

Unfortunately, the gains obtained through these comprehensive care programs are not threatened. As you just mentioned, acquired immune deficiency syndrome, or AIDS, is a new risk for individuals exposed to blood products; and hemophiliacs are at a special risk because of the transmission of the responsible agent in the coagulation factor concentrates.

There are now 30 CDC confirmed cases of AIDS among the 9,000 hemophilic patients with a severe factor deficiency that requires frequent treatment. This is an incidence during a 2-year period of 1 case for every 300 patients.

Thus the risk of AIDS is higher in severe hemophiliacs than in any other group. This fact touches all of us.

But imagine your response, however, if you needed to infuse a clotting factor concentrate two or three times a week to treat or avoid painful bleeding episodes. Imagine your response if your son had to be infused regularly to avoid crippling.

This is a difficult, frustrating, and frightening situation; and frequent contacts with doctors and nurses are essential. The patients do not have an option. Continued use of the clotting factors is necessary to prevent progressive disability.

They are obligatory recipients of blood products that have the potential for AIDS transmission. Thus the National Hemophilia Foundation has a special interest in efforts to understand and control AIDS.

These two major issues that I've addressed can be translated into the following appropriation requests. First, we urge you to appropriate $4.6 million for fiscal year 1985 to support the Hemophilia Comprehensive Treatment Center Program. While this is a $1.7 million increase over the current funding level, it is essential if regional treatment center comprehensive care programs are to reach all patients and to provide the necessary services.

We also request that the 15-percent set-aside be maintained within maternal and child health appropriations. The Hemophilia Treatment Center Program crosses State lines. Every regional center is responsible for care of patients from more than one State. It is clearly a special program of regional and national significance.

Second, we are deeply concerned that there be adequate funding for basic biomedical research sponsored by the National Institutes of Health. We very much appreciate the farsighted efforts of Congress last year in providing a significant increase in research support which addressed a previous lag in funding.

In conclusion, I want to emphasize that comprehensive care and research were never more important. These issues are of concern to every citizen and especially the 18,000 patients with hemophilia and their families. Thank you.

Senator INOUYE. Thank you very much. I'm certain if the chairman were here he would tell you how supportive he is. As you know, he has been very supportive, but he sends his regrets to all. He has another committee assignment so we are sitting in for him.

Is there any possibility that in some near future you'll have some artificial drug that can be used to assist in the coagulation?

Dr. HOYER. I think it's quite likely. Now, I'm really talking about two separate proteins; one, factor 9, which is the protein deficient in the minority of the patients, 20 percent of them. The progress in gene cloning has been very satisfactory in that area and I would think that within perhaps 5 years it's quite likely that that will be available through the coming pathology.

Senator INOUYE. The moneys that you mentioned would cover this type of research?

Dr. HOYER. This research is going on based, now, on basic research that the NIH sponsored years ago and, to a large extent at the present, in private firms. They sense this as an important issue and are working very hard at it.

The more difficult problem is the antihemophilic factor, the deficiency in 80 percent of the patients, because this is a very large and very difficult protein. There is a great deal of research going on, but one can only have a modest confidence that this will be available in less than 5 or 10 years.

But it is perhaps one of the highest goals of people working in the recombinant technology today because it not only would have a tremendous influence in treating these patients, but would avoid the problems of plasma transfusion and AIDS.

Senator INOUYE. Well, I thank you very much, sir.

Dr. HOYER. Thank you.

STATEMENT OF ANTHONY RENDA, MEDICAL AND SCIENTIFIC LIAISON, REPRESENTING NUNZIO CAZZETTA, VICE PRESIDENT, COOLEY'S ANEMIA FOUNDATION

PREPARED STATEMENT

Senator INOUYE. Our next witness is the vice president of Cooley's Anemia Foundation, Nunzio Cazzetta. Welcome sir.

Mr. RENDA. Thank you, Mr. Chairman. Mr. Cazzetta could not be here today so I would like to fill in for him. My name is Anthony Renda.

Senator INOUYE. R-e-n-d-a?

Mr. RENDA. R-e-n-d-a.

Senator INOUYE. Yes, sir.

[The statement follows:]

STATEMENT OF ANTHONY RENDA

Mr. Chairman, thank you for permitting me to testify for the seventh year regarding appropriations for research and care in Cooley's Anemia. I am Nunzio Cazzetta, a member of the Executive Committee of the Board of Directors of the Cooley's Anemia Foundation.

As we have reported to you a number of times on Cooley's Anemia, we are fully aware that you understand the disease and its implications medically and socially for our children. I have, however, attached to this testimony a brochure explaining Cooley's Anemia and the work of the Foundation in relation to it.

Because of the support of your Appropriations Subcommittee, there have been very remarkable gains in research and also in care concerning Cooley's Anemia patients, and we are very deeply grateful to you and to your colleagues for that support.

Every year, at our annual meeting for our Foundation volunteers, reports are given on the research advances made at the NIH, and specifically at the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, and the National Heart, Lung and Blood Institute, as well as care programs funded by the Maternal and Child Health agency.

Attached to this testimony is a fact sheet of our recommendations for the committee for this year, and I list them now in this testimony:

1. That bill report language call for a comprehensive survey of Federal and Federally-supported state programs which now exist (including the Department of Health and Human Sercices, the Department of Education, and the Department of Labor) which would be helpful in serving Cooley's Anemia families, chapters and advisors of patients who, because of improved medical care, are living longer and now require assistance with job training, education and tutoring (because of time spent in hospitals and at home recuperating from medical problems), social adjustment and counseling, and similar needs. (We will be pleased to supply suggested bill report language to the committee, if desired.)
2. That bill report language stress the need for blood research continuing in a number of institutes at the NIH. The NHLBI and the NIADDK both

have programs for research on Cooley's Anemia and other blood disorders (as many as eight different institutes are concerned with different kinds of research on diseases of the blood), and we believe that as they deal with different aspects of such research that multiple funding systems should be continued (see statement of the Medical Advisory Board of the Cooley's Anemia Foundation);

3. That funding levels for the Maternal and Child Health program be sufficient to fund Cooley's Anemia programs now under way (part of the 15% "set-aside," furnished as a program of "regional and national significance") in New York State and New England, and that the 15% "set-aside" be recognized to be continued in the bill report;
4. That the National Heart, Lung and Blood Institute be funded at $815 million for FY 1985;
5. That the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases be funded at a level of $550 million for FY 1985; and
6. That the two above-named institutes be urged to continue their support of the rapidly evolving areas of research on Cooley's Anemia.

I would like at this point to deal with the most serious concerns that we have this year.

1. We would like this committee to know that in the bill H.R. 2350, the Health Research Extension Act of 1983, passed by the House on November 17, 1983, there was a provision which would have in a sense deleted the effectiveness of hematology research from the NIADDK.

   (The Senate bill does not have a similar exclusion of blood research from the NIADDK.)

   We recognize that this committee does not authorize legislation, but you do appropriate funds for blood research. This is a very serious matter for us, as we believe that it would seriously cripple the on-going activities of the NIADDK in hematology research.

   At our December meetings just a few months ago, the Medical Advisory Board of the Cooley's Anemia Foundation expressed its very grave concern about this matter, and I would like to tell you now what the formal resolution of the Medical Advisory Board said:

"RESOLVED: That the Medical Advisory Board of the Cooley's Anemia Foundation expresses its grave concern that H.R. 2350, recently passed by the U.S. House of Representatives, if agreed to by the Senate and signed into law, would inadvertently seem to weaken significantly the research program in hematology currently undertaken by the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases.

"In that bill, hematology research has been deleted, in the first paragraph, stating the Institute's mission, as one of those areas of research to be undertaken by the NIADDK, both intramurally and extramurally, and the title of the Director of Kidney, Urological and Hematological Research has been replaced with the title of Director of Kidney Research.

"We do understand that within the body of the legislative language, hematology research is sufficiently stressed so that the National Institutes of Health would probably be within the law to continue such research, but we believe that it would be appropriate for the Congress to return to the language of the present law, so that hematology research can continue to be conducted on a firm legislative authorization base, and so that researchers currently in the field, and research trainees and fellows who will be the leaders of the field in the future, are reassured that such research should go forward unhampered by uncertainty.

"We also request that explanatory bill report language in support of hematology research in the institute accompany the legislative language.

"In support of the continuation of such research, we note:

- that this Institute has supported such research for over 30 years, since 1950;
- that following passage of PL 92-414, the "National Cooley's Anemia Control Act," the NIADDK increased its research on Cooley's Anemia; and
- that an extensive evaluation of research in hematology has just been completed by the NIADDK with the publication of "Research

Needs in Hematology," which will assist in the design of research programs in this Institute for years to come."

Also, the Medical Advisory Board put together a fact sheet on this situation regarding support for hematology research in the NIADDK, and I attach that to this testimony, and request that it become part of the record.

I know that my colleagues in the American Society of Hematology, as well as in the National Hemophilia Foundation will support this concern, and will also support my request that there be inserted bill report language indicating that blood research is carried on at numerous institutes within the NIH, and that that should be continued.

2. We know that the Administration is proposing legislation (not yet introduced) that would do away with the so-called 15% "set-aside", which funds are used for a nationally administered set of programs of regional and national significance, which includes the two programs currently underway as part of the so-called "SPRANS" program of the Maternal and Child Health Administration. We are hopeful that this committee will put language into the bill report which calls for continuation of the 15% set-aside, and we hope that that language will specifically recognize the continuation of the so far extremely successful Cooley's Anemia programs in New York State and in New England.

The Foundation has been impressed with the implementation of those two Cooley's Anemia programs, and we believe that the so-called "SPRANS" program, administered at the national level is helpful to other programs as well, including those in other blood disease areas. It is our understanding that this program supports over 300 projects, fostering research, training, genetics, and other special project activities which are of great importance. As I say, speaking from our own experience, the Cooley's Anemia programs have been very helpful to the patients and their families. These two projects are not only incorporating the newer treatment and management techniques into on-going services for these patients, but are also demonstrating the ability of this type of improved medical care to extend the life expectancy of these patients. It is our hope that increased appropriations for this program will permit transfer of the experiences of the demonstrations in New York and New England to other service sites where Cooley's Anemia patients desperately need this type of care. Of course, we are hopeful that the New England and New York programs will continue their excellent work.

3. Last year in the Supplemental Appropriations Bill for 1983, the Senate, in its bill report 98-148, made this statement about the need for a comprehensive survey of the newly emerging needs of patients and their families, in relation to Cooley's Anemia:

"The Committee has learned that because of increasingly improved care resulting largely from biomedical and clinical research and care programs, some Cooley's Anemia patients are living in relatively good health, into their second, third, and fourth decades of life. This longer life span creates both opportunities and problems for Cooley's Anemia victims in a variety of areas which need to be addressed. The Committee requests that the Secretary of Health and Human Services, in consultation with the Cooley's Anemia Foundation and the federally-assisted Cooley's Anemia projects in New York and New England, carry out a comprehensive survey of the newly emerging needs of patients and their families. In addition, the Committee suggests that the Secretary consider developing clinical service programs in other regions of the country to provide access to care for scattered concentrations of the at-risk group, particularly in areas where there are concentrations of Asian immigrants. This will help document the prevalence of Cooley's Anemia in that population."

We believe that this program is moving forward reasonably well, and now request that this committee consider the possibility of additional bill report language which would call for a comprehensive study of the needs of Cooley's Anemia patients in areas such as education, tutoring, training for work, counseling, etc., and request that there be established a comprehensive survey of federal and federally-supported state programs which now exist which could serve these needs. We believe that the Department of Education, the Department of Health and Human Services, and the Department of Labor could participate in pulling together those programs which they already administer or support, and supply for the public a form of directory of these services.

The other items that are considered of importance to us have been reported earlier in the listing of our fact sheet concerns.

I would like to take this opportunity to insert into the record also, Mr. Chairman, research progress reports for 1983 for both the National Heart, Lung and Blood Institute, and the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases.

RESOLUTION: CONCERNING CONTINUATION OF COOLEY'S ANEMIA RESEARCH IN NIADDK

December 5, 1983

RESOLVED: That the Medical Advisory Board of the Cooley's Anemia Foundation expresses its grave concern that H.R. 2350, recently passed by the U. S. House of Representatives, if agreed to by the Senate and signed into law, would inadvertently seem to weaken significantly the research program in hematology currently undertaken by the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases.

In that bill, hematology research has been deleted, in the first paragraph, stating the Institute's mission, as one of those areas of research to be undertaken by the NIADDK, both intramurally and extramurally, and the title of the Director of Kidney, Urological and Hematological Research has been replaced with the title of Director of Kidney Research.

We do understand that within the body of the legislative language, hematology research is sufficiently stressed so that the National Institutes of Health would probably be within the law to continue such research, but we believe that it would be appropriate for the Congress to return to the language of the present law, so that hematology research can continue to be conducted on a firm legislative authorization base, and so that researchers currently in the field, and research trainees and fellows who will be the leaders of the field in the future, are reassured that such research should go forward unhampered by uncertainty.

We also request that explanatory bill report language in support of hematology research in the institute accompany the legislative language.

In support of the continuation of such research, we note:

--that this Institute has supported such research for over 30 years, since 1950;

--that following passage of PL 92-414, the "National Cooley's Anemia Control Act," the NIADDK increased its research on Cooley's Anemia; and

--that an extensive evaluation of research in hematology has just been completed by the NIADDK with the publication of "Research Needs in Hematology," which will assist in the design of research programs in this Institute for years to come.

FACT SHEET: SUPPORT OF HEMATOLOGY RESEARCH BY THE NIADDK (NIH)
(Attachment to Medical Advisory Board Resolution)

The National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases supports hematologic research, involving diseases of blood and blood-forming organs, as a part of its mission to eliminate the threat to the Nation's health from the chronic diseases that cause suffering, disability, and early death. Many of these chronic diseases exhibit manifestations which include anemia, including Cooley's Anemia, caused by impaired blood production or faulty construction of the red blood cells.

The anemia of chronic renal disease occurs in most of the 65,000 chronic renal disease patients treated annually in the U.S. Anemia is commonplace in patients with endocrine disorders, the collagen diseases, rheumatoid arthritis, ulcerative colitis and other digestive diseases, liver disorders, and inflammatory syndromes. These anemias, all of which are acquired secondary to chronic diseases, fall within the NIADDK responsibility, not only because of the basic hematologic involvement, but also because of the NIADDK mission related to kidney disease, diabetes and other endocrine disorders, arthritis, and digestive and liver diseases.

Other Institutes, including the National Heart, Lung and Blood Institute, and the National Cancer Institute, support research on blood as important components of their respective missions. The programs of all these institutes are complementary, and guidelines for the assignment of responsibilities are carefully negotiated to avoid duplication of effort.

The NIADDK Hematology Program emphasizes the mechanisms of normal blood cells function and their alterations in disease processes; the NHLBI is most concerned with fundamental hematologic research and its clinical applications, and the NCI is deeply involved with research on malignant alterations of blood cells and how both to treat these disorders and support the patients while they receive anti-cancer therapy.

The NIADDK has conducted intramural research and supported extramural research on hematologic diseases since the formation of the Institute in 1950.

The focus always has been to seek to prevent or cure hereditary or acquired disorders of blood cell formation or metabolism. In addition, blood cells have been studied as a convenient biological tool for research into other basic and clinical phenomena.

In 1971, Hematology was placed under the Associate Director for Kidney, Urologic and Hematologic Diseases. A major emphasis, then and now, has been basic work on the hemoglobin molecule, which has been instrumental in establishing concepts in molecular disease, using sickle cell anemia and Cooley's Anemia as important models. In 1971, the number of applications dealing with sickle hemoglobin nearly doubled from the previous year, as a result of announced emphasis on sickle cell disease. The NIADDK still supports research on basic genetic and structural aspects of hemoglobin, some of which bears generally on sickle cell disease. Following passage in 1972 of PL 98-414, known as the "National Cooley's Anemia Control Act", the NIADDK increased its emphasis on Cooley's Anemia. Currently, the NIADDK supports basic research on the mechanism of the causal genetic defect in hemoglobin synthesis, and is working to develop new iron chelating drugs for ameliorating the effects of transfusion therapy for Cooley's Anemia patients. The NIADDK has been active in conducting and supporting essential research on plasma clotting factors and hemophilia, bone marrow transplantation, and nutritional and iron storage diseases related to the blood. An extensive evaluation of research in hematology has just been completed by the NIADDK with the publication of a final report, "Research Needs in Hematology". It is expected that this report will assist the NIADDK and other concerned Institutes in the design of their research programs for years to come.

The following represents total NIADDK Hematology Program expenditures for years since Fiscal Year 1967, for which consistent and comparable figures are available.

Fiscal Year	Total Extramural Hematology Dollars (in thousands)
67	$ 10,308
68	10,321
69	10,416
70	10,309
71	10,951
72	11,971
73	11,111
74	11,799
75	12,543
76	12,168
77	12,651
78	15,191
79	18,121
80	19,777
81	22,260
82	22,285
83 (est.)	25,083

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

Cooley's Anemia Research Progress - 1983

A Mouse Model for Cooley's Anemia

The first animal model for Cooley's anemia has recently been discovered and characterized. A DNA deletion including regulatory sequences and coding blocks results in a deficiency of beta-globin production and produces hematologic abnormalities similar to those observed in Cooley's anemia patients. The discovery of this mouse model is particularly timely for furthering the development of gene therapy. Several techniques have been proposed for introducing normal genes into mutant cells but many technical problems remain to be addressed regarding the proper regulation and expression of the new gene. The hematopoietic system of the mouse allows a unique opportunity to study genetic manipulation in vivo. After in vitro transfer of the new genetic material into the pluripotent stem cells of the diseased mice, standard bone marrow transplantation will then allow the new genetic material to be introduced into the mouse. The succes of the various genetic manipulations can be easily monitored by analysis of the hemoglobins produced and correction of the genetic disease. Regulation of the transferred gene will be a critical factor since the rate of synthesis of beta-globin must precisely match that of the alpha-globin portion of hemoglobin. A beta:alpha globin ratio which is too low would not correct the disease and a high ratio would be toxic.

Bone Marrow Transplantation for Cooley's Anemia

In 1982, the University of Washington reported the first successful bone marrow transplant for Cooley's anemia. The patient was a previously untransfused 16-month-old child who is now cured of the disease. Since then, bone marrow transplantation has been performed in 22 thalassemic patients in Europe. These early results indicate that graft failure or rejection occurred in 57% of the cases. A group at Memorial Sloan-Kettering in New York recently reported a successful transplant performed on a heavily transfused 7-year-old thalassemic. The only problem encountered has been chronic grant-vs.-host disease (GVHD) which is under control in this patient. However, the primary cause of death from bone marrow transplantation is GVHD and this remains as the major obstacle to be overcome before the widespread use of this procedure for curing Cooley's anemia. In experiments in mice, removal of donor T cells (the cells responsible for causing GVHD) will prevent GVHD but similar attempts in humans have been disappointing. Investigators at the University of Minnesota have prepared powerful immunotoxins composed of an extremely potent poison (ricin) linked to a monoclonal antibody that recognizes only donor T cells. Pilot studies in three transplant patients are underway and results so far look encouraging.

(Although this bone marrow transplantation research has not been funded by the NHLBI, we at the Cooley's Anemia Foundation, nevertheless, are following progress in this area with great enthusiasm.)

Neocyte Transfusions for Cooley's Anemia

It has been several years since the introduction of neocyte transfusions for Cooley's anemia. Results of a clinical trial at Children's Hospital of Philadelphia indicate that neocyte transfusions can reduce the total transfusion requirement by 16%. However, the investigators concluded that at their institution, a 16% reduction in blood requirement would not be cost effective since it requires two units of red cells to repair one unit of neocytes. Additionally, technician expenses and supplies add to the cost ($73 for a unit of neocytes as compared to $26 for packed red cells of equal mass). A group at Columbia in New York, in collaboration with a team at Boston Children's Hospital, have predicted a 30% reduction in blood transfusion requirement using neocytes and a cooperative clinical trial is underway. In addition, the Boston group is developing a blood bag system to allow routine preparation of 4 units of neocytes in a single 15 minute operation. If successful, this should decrease the cost of preparing neocytes and may be cost effective even at a 16% reduction in blood requirement.

Synthesis of Fetal Hemoglobin

In order to compensate for the diminshed or absent adult hemoglobin in Cooley's anemia patients, scientists have been exploring ways to "turn on" the production of fetal hemoglobin. Last year we reported that the drug, 5-azacytidine, was shown to be successful in stimulating the production of fetal hemoglobin in patients with Cooley's anemia and sickle cell anemia. However, this drug is believed to be toxic and similar types of agents are being sought. One such drug, hydroxyurea, has been used in three patients and preliminary unpublished results look encouraging. The toxicity of hydroxyurea remains to be determined.

First Trimester Prenatal Diagnosis

A new procedure known as chorionic villus biopsy may replace amniocentesis as a technique for obtaining fetal cells for prenatal diagnosis of Cooley's anemia and other genetic diseases. Amniocentesis cannot be performed before the sixteenth week of gestation and it takes two weeks to obtain the results. Chorionic villus biopsy can be performed between eight and ten weeks of pregnancy and results are obtained within days or even hours. The advantage of this new technique is that it is done early in pregnancy, when it is safer to abort should a woman choose to do so. Chorionic villus biopsy is still an experimental procedure and the safety of the technique remains to be determined.

NATIONAL INSTITUTE OF ARTHRITIS, DIABETES, AND DIGESTIVE AND KIDNEY DISEASES

Cooley's Anemia Research Progress - 1983

The NIADDK Hematology Program continues to emphasize research into the cause of Cooley's anemia and into developing methods to treat, prevent or cure the disease. In Fical Year 1983, the NIADDK supported 32 research grants and 5 contracts related to Cooley's anemia, for a total of more than $5 million.

Considerable progress has been made recently in understanding the cause of Cooley's anemia at the genetic and molecular level. Of the many known causes, the most common is an abnormally low amount of messenger RNA, which carries genetic information to the site of hemoglobin synthesis. The globin genes of affected patients appear to be normal, but the genetic mechanism of RNA synethesis now has been found to be abnormal. This genetic error may be the basis of the disease in most patients of Mediterranean origin.

Since Cooley's anemia is a disorder involving the adult form of hemoglobin, other forms, including fetal hemoglobin, are not affected. Intensive efforts to increase the amount of fetal hemoglobin in the circulation of adult Cooley's anemia victims have been successful with the experimental use of the drug, 5-azacytidine. The increase in fetal hemoglobin synthesis following 5-azacytidine administration is dramatic and the clinical status of the patients is temporarily improved. Much needs to be learned about this and other potentially useful drugs, but the demonstration of an active drug has been encouraging.

Direct DNA analysis has been applied to fetuses at risk for Cooley's anemia at a very early stage in development. Synthetic DNA probes can detect abnormal hemoglobin in fetal cells taken from the amniotic fluid as early as the 16th gestational week. A few laboratories have reported the analysis of DNA obtained from the placenta at 6 to 8 weeks of pregnancy. These procedures appar to be rapid, accurate, and safe, and are likely to make prenatal diagnosis more acceptable to concerned couples.

A safe noninvasive magnetic device (SQUID) has improved considerably the measurement of liver which iron stores in Cooley's anemia patients with transfuctional iron overload. Further improvement, including the ability to measure iron in the heart, will allow the monitoring of patients and the rapid evaluation of treatment regimens. In related efforts to find ways to reduce iron overload, the NIADDK has continued to search for more effective iron chelating agents. One potentially oral drug is undergoing studies to determine toxicity, with a second very effective compound to be examined shortly.

An NIH session on New Research Approaches to Cooley's Anemia Therapy will be held in conjunction with the New York Academy of Sciences Fifth Cooley's Anemia Symposium in New York in June, 1984. This session, organized by the NIADDK and NHLBI, will bring together prominent investigators to discuss promising new directions, and to identify research needs and research problems.

Mr. RENDA. I am a member of the executive committee and a medical and scientific liaison of the Cooley's Anemia Foundation. I'm also the president and research chairman of the Cooley's Anemia Volunteers, Inc. And my most important qualification is I'm also a patient with Cooley's anemia.

The two gentlemen to speak before me dovetailed very nicely with what I would like to address today. We heard Dr. McCurdy thank the Congress for the support they've given on behalf of the researchers.

I would like to take this opportunity to thank the Congress for funding which we are the beneficiaries of, the patients. We see much success in the last few years and I would just like to, again, thank the Congress for this.

I would like to begin with perhaps the briefest of definitions of what this disease is. Cooley's anemia is an inherited genetic blood disorder which results in insufficient production of blood, which then will require continuous periodic blood transfusions to maintain life.

Complications of the disease and the blood transfusion treatment result in excessive and fatal damages to the endocrine, immunological, hepatic, and cardiac systems. That's the most basic definition I can give you.

I average transfusions every 2 weeks. Some patients are every 3 weeks.

Senator INOUYE. What quantity?

Mr. RENDA. Two units of washed red cells. So this is something which is a weekly occurrence in our life.

To summarize the Cooley's anemia written testimony, I would like to say that we request for fiscal year 1985 appropriations action that would, first, provide bill report language to call for a comprehensive survey of Federal and federally supported State programs which now exist, which would be helpful in serving Cooley's anemia families, service organizations, and the patients themselves who because of improved medical care now find themselves in the position of living longer and dealing with a whole new set of problems.

Some of the issues that need to be addressed now for the first time in Cooley's anemia patients are assistance programs for education, job training, career planning, social adjustments, and counseling.

Second, that bill report language stressed the need for continued blood research in a number of the institutes of the NIH, most specifically the National Heart, Lung, and Blood Institute and the National Institutes of Arthritis, Digestive Diseases, Kidney Diseases.

Both of these organizations currently are running programs for us and we believe that as they do with different aspects of the disease multiple funding for both of these institutions should be continued.

We also feel, as was mentioned by the gentleman from the hemophilia organization, that the funding levels for the maternal and child health programs to fund Cooley's anemia programs under the 15-percent set-aside, which are currently underway in New York State and New England, should be continued.

We also request that the National Heart, Lung, and Blood Institute be funded at $788 million for fiscal year 1985; that the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases be funded at a level of $550 million for fiscal year 1985; and that the above two named institutions be urged to continue their work specifically in Cooley's anemia.

Now, if I may take another minute I would like to expound a little bit on what we feel is our main priority for testifying here today.

Last year in the supplemental appropriations bill for 1983 the Senate, in its bill report, 98–148, made this statement about the need for a comprehensive survey of the newly emerging needs of patients in relation to Cooley's anemia; and I quote:

> The committee has learned that because of increasingly improved care, resulting largely from biomedical and clinical research and care programs, some Cooley's anemia patients are living in relatively good health into their second, third, and fourth decades of life. This longer lifespan creates both opportunities and problems for Cooley's anemia victims in a variety of areas.

As I mentioned before, those areas are problems which we're seeing for the first time. In the last 5 to 10 years, the average life expectancy of the Cooley's anemia patient in this country was early to middle teens. We now have patients reaching their twenties and thirties.

College for the first time. Continuing education has become a problem. Economic stability for patients who are becoming independent of their parents has become, in some areas, a problem.

Career planning. Job training has become a problem. And for the first time we have patients who are now approaching marriage and family considerations.

All these areas are new to the Cooley's anemia community and, for this reason, we would request that a comprehensive survey be conducted to identify and understand these newly emerging problems which are hitting us for the first time.

We would like to see, as a followup to this survey, an additional survey to provide information about where we can receive help from existing Federal and federally funded State programs which can be made use of by Cooley's anemia patients and families with the ultimate goal of providing a directory of resources.

Senator INOUYE. May I suggest that at your earliest you get together with the staff of this committee and draft appropriate language for the committee.

Mr. RENDA. We would be more than pleased to do that.

Senator INOUYE. I can assure you, as one member, that report language will be part of the report.

How many patients do we have in the United States, Cooley's anemia patients?

Mr. RENDA. Patients with the more serious form of the disease who require——

Senator INOUYE. Oh, any.

Mr. RENDA [continuing]. Continual transfusions number somewhere between 2,000 and 5,000 with the very severe diseases. We find new patients daily.

People outside of the major medical centers are still finding that patients are not identified as Cooley's anemia. They're being misdiagnosed. The population at risk, however, is much, much greater in this country.

The population at risk has been identified to be those people with their ancestry from the Mediterranean region, Africa, and now Asia.

We find a big influx with the Asian populations now moving into this country.

Senator INOUYE. So approximately how many are either affected or touched by this disease?

Mr. RENDA. At risk populations run close to the million mark, now, in this country.

Senator INOUYE. Well, we'll do all we can, sir.

Mr. RENDA. Thank you.

STATEMENT OF DR. THOMAS J. RYAN, PROFESSOR OF CARDIOLOGY, BOSTON UNIVERSITY; AND PRESIDENT-ELECT OF THE AMERICAN HEART ASSOCIATION

PREPARED STATEMENT

Senator INOUYE. Our next witness is the president-elect of the American Heart Association, Dr. Thomas J. Ryan.

Welcome, Dr. Ryan.

Dr. RYAN. Thank you, Senator Inouye.

[The statement follows:]

STATEMENT OF DR. THOMAS J. RYAN

Mr. Chairman, I am Dr. Thomas Ryan, Chief of the Section of Cardiology at the University Hospital of Boston University School of Medicine, where I am a Professor of Medicine. I appear today on behalf of the American Heart Association -- its 120,000 voluntary leaders, 40,000 scientific members and over two million program and fundraising volunteers. As the current President-elect of the American Heart Association, I am very pleased to have this opportunity to offer the following comments and funding recommendations for Federal programs pertaining to cardiovascular disease research and prevention.

We are very grateful to the Labor, Health and Human Services and Education Appropriations Subcommittee for your consistent support of Federal programs in biomedical research, as well as those designed to facilitate the transfer of new scientific knowledge into public and private sector prevention and education efforts. Your continued support of these programs will help ensure a healthier future for all Americans.

The National Institutes of Health (NIH) is truly a national treasury of scientific and technological capability that, since mid-century, has brought our nation to a position of scientific leadership second to none in the world. The American Heart Association is pleased that its own programs in biomedical research, education and prevention also have contributed to this leadership.

Over the past four decades we have witnessed an unparalleled knowledge explosion in the biological and medical sciences. In our view, the scientists, administrators and managers at the NIH have succeeded to a spectacular degree in keeping its research programs abreast of these developments -- and frequently on their cutting edge. We are deeply concerned, however, that inadequate funding, rather than any lack of scientific opportunity or initiative, may slow the momentum of the expanded effectiveness in our nation's research enterprise.

The President's proposed increase of 2.2 percent for the NIH in FY 1985 falls far below the increases requested for other Federal research programs: National Science Foundation, 14 percent; Department of Defense, 15 percent; Department of Energy, 18 percent; and the National Aeronautics and Space Administration, 16 percent.

Furthermore, although the President's request does include funding for 5,000 competing research grants, it does so at the expense of other NIH program mechanisms. It must be emphasized that this so-called 5,000 "target" for competing research grants supported by NIH evolved as a floor below which the number must not fall in order to ensure continuous biomedical research momentum in the future. With regard to the research training program at NIH, the President's budget includes a request for 9,000 pre- and post-doctoral trainee positions, including the provision of a 5% stipend increase for post-doctoral trainees. While this 5% increase is a step in the right direction, it does little to make NIH pre-doctoral stipends competitive with stipends in other Federal agencies, such as the Department of Defense, or to close the wide gap that exists between stipends for NIH M.D. trainees and private sector salaries offered to medical house staff. If we wish to continue to attract the brightest individuals into the various fields of biomedical research we must raise this unacceptably low level of stipend support from NIH.

We urge the subcommittee to recommend, for FY 1985, an increase of 16 percent over FY 1984 funding for the National Institutes of Health. This would (1) allow for real growth in the research programs of NIH; (2) encourage young M.D.'s and Ph.D.'s to pursue research careers by funding 10,000 NSRA fellows at increased stipend levels; (3) allow for the initiation of important new clinical trials and population studies, and (4) begin to alleviate the serious problems of shortages and obsolescence in research equipment and instrumentation.

We believe the public would support such an increase. A recent Lou Harris Poll showed that 68 percent of those surveyed believes that Federal funding of basic research should be increased substantially. Furthermore, 82 percent indicated that even if basic research achieves no immediate results, it is worth the present investment.

Since 1948, the American Heart Association and the NHLBI have been active partners in the battle against cardiovascular disease. Throughout this 35-year partnership, the research, training, education and community programs of both the AHA and the NHLBI have had significant impact on diseases of the heart and circulation -- the Nation's leading cause of death.

The NHLBI program, in fact, encompasses four of the Nation's ten leading causes of death. Together, these diseases account for 53 percent of all mortality in the United States and claim more than one million American lives each year. The total economic burden of these diseases is estimated to be in excess of $100 billion annually. This is more than 35 percent of the total cost of illness in the United States, based on 1980 dollars.

As alarming as these statistics may be, there are some positive trends as well. Since 1968 -- due in large part to scientific advances made in the 1950's and 1960's -- NHLBI has demonstrated remarkable program effectiveness. The death rate from coronary heart disease has decreased by 32 percent. The death rate from stroke has plummeted by 46 percent. The death rate from all cardiovascular diseases has decreased by 33 percent. During this same period, the death rate from all other diseases decreased by only 13 percent.

This decline in the death rate has resulted in the savings of more than a million American lives -- and a significant savings in tax dollars. It has been estimated that for each dollar spent in biomedical research, there is a return of $10 to $16 in reduced illness and medical costs, due to increased life expectancy. But we must not become complacent as a result of these past accomplishments.

It is estimated that over 42 million Americans have one or more form of cardiovascular disease. High blood pressure afflicts an estimated 37 million adults. Diseases of the heart and blood vessels kill almost as many Americans each year as all other causes combined -- in 1981 this toll reached nearly one million deaths.

The outstanding program effectiveness of NHLBI is a potent weapon in the fight against heart disease and deserves further mention. The Institute's Advisory Council and the scientific community, over the years, have paid careful attention to the need for a balanced approach to the evolving program structure of the NHLBI. Although a high priority is given to the funding of research program grants, the NHLBI also stresses other program mechanisms, such as clinical trials, population studies, specialized centers of research (SCORs), national research and demonstration centers, research career and training awards and research and development contracts.

AHA believes that this careful balance of programs has enhanced NHLBI effectiveness as a scientific leader in cardiovascular research. However, we must again voice our concern about the impact of inadequate funding on continued program advancement. Between 1972 and 1982, total funding of the NHLBI did increase by $335.5 million. But, in constant dollars, the actual increase during this ten-year period was only $36.4 million.

We realize that allocation decisions become more difficult when funds are restricted and we commend the NHLBI for its ability to maintain high program standards in times of fiscal constraint. We are also confident that the NHLBI will continue to allocate resources to the major areas of on-going research opportunity. However, in order to ensure continued effectiveness, funding of NHLBI programs must be sufficient to allow for expansion into new and emerging fields of cardiovascular research as well. In order to continue the downward trend in cardiovascular disease death rates promising new initiatives, now ready for study or implementation, must not be deferred due to lack of funds. To cite a few:

- Follow-up of the recent Lipid Research Centers - Coronary Primary Prevention Trial (LRC-CPPT). This landmark clinical trial has shown for the first time that the reduction of elevated blood cholesterol can result in a significant reduction in the risk for heart attack. Prompt and effective follow-up by the NHLBI holds great promise for future reduction of premature death and disability from coronary heart disease.

- Expansion of current Ischemic Heart Disease - Specialized Centers of Research (IHD-SCORs) into national research and demonstration centers. This would encourage new approaches in disease prevention, health promotion and improved health care practices.

- Community surveillance system for cardiovascular disease. This would help measure the effects of public and private sector prevention efforts, changes of life styles and improvements in medical and surgical therapies on the incidence of cardiovascular disease.

- Continuation and expansion of the current Hypertension SCOR program. This would allow for expansion of multidisciplinary clinical and basic research into the causes, prevention and control of hypertension.

- Research on hypertension in pregnancy. Hypertension in pregnancy accounts for 25,000 stillbirths and neonatal deaths and 20% of maternal deaths annually. Further research will help determine the causes and improve clinical management of this condition.

- Investigation into the relationship between obesity, blood pressure and blood lipids. Study of the biological mechanisms involved will aid in the treatment and prevention of obesity and cardiovascular disease.

- Study of biobehaviorally induced ventrical arrhythmias. Understanding of psychophysiologic factors in life-threatening ventricular arrhythmias will lead to the development of protective intervention therapies and the reduction of sudden cardiac death.

The American Heart Association believes that, when one objectively considers the magnitude and scope of the health problems NHLBI addresses, the cost of these problems to our nation in American lives and dollars and the remarkable progress NHLBI has made in preventing premature death and disability, then one can only include that the NHLBI merits the highest priority of funding support by the Congress.

We are convinced that recent gains in our understanding of the mechanisms and treatment of cardiovascular diseases now bring new research opportunities that hold a high potential for continued progress by the NHLBI against our nation's most serious health threats.

When all these factors are considered, we must admit that we are appalled that the President's FY 1985 proposed budget includes only a 2.2% increase for NHLBI over FY 1984 levels, an increase well below the rate of inflation for biomedical research and development programs. The impact of the President's FY 1985 budget on the NHLBI program would be devastating. To cite a few examples:

- New and competing research grants at NHLBI would be cut from 729 to 682, and grants would be funded approximately 8 percent below recommended levels.
- Non-competing research grants would be funded 13 percent below recommended levels.
- NHLBI SCOR programs would be cut by 5 percent and no new funds would be provided for enhancement activities.
- Other research-related grants funded by NHLBI would be cut by 5 percent.
- NHLBI training positions would be reduced from 1620 to 1409.

We call on the Subcommittee to approve an appropriation for the NHLBI for FY 1985 in the amount of $815.7 million. This is as increase of 16 percent over FY 1984, which is consistent with FY 1985 increases proposed for other Federal research programs. We believe this level of funding would allow the NHLBI to continue momentum in the major areas of research and to undertake new initiatives with a high potential for success.

In summary, we would urge that this Subcommittee accord a high funding priority for FY 1985 appropriations for the biomedical research programs of the National Institutes of Health by appropriating the following amounts for:

- THE NATIONAL INSTITUTES OF HEALTH -- $5,200,000,000 FOR ALL PROGRAMS.
- THE NATIONAL HEART, LUNG AND BLOOD INSTITUTE -- $815,700,000 FOR ALL PROGRAMS.

Our funding recommendations for other programs of concern to AHA which fall under the Subcommittee's jurisdiction include:

- THE NATIONAL INSTITUTE OF NEUROLOGICAL AND COMMUNICATIVE DISORDERS AND STROKE. -- $388.8 million of which $3.05 million would be for the creation of four additional stroke centers and 3 stroke demonstration units at existing centers in FY 1985.
- THE NATIONAL LIBRARY OF MEDICINE. -- $58.2 million
- PREVENTIVE HEALTH SERVICES BLOCK GRANT. -- $97.02 million
- OFFICE OF SMOKING AND HEALTH. -- $4.0 million
- OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION. -- $3.54 million

Dr. RYAN. I am Dr. Thomas Ryan, professor of cardiology at Boston University School of Medicine and president-elect of the American Heart Association. I appear before this subcommittee on behalf of the 2.2 million members of the Heart Association and express my personal thanks for the opportunity of coming before this committee.

The Heart Association is grateful to this subcommittee for its consistent support of Federal programs to support biomedical research over the past and we are here to urge you to continue that support. The sentiment we have is, I think, universally appreciated that the NIH is a unique national resource and has kept this country at the very cutting edge of scientific achievement. We feel that the momentum to continue to do so hinges critically on appropriate funding.

Our concern in the Heart Association is that inadequate funding is just going to widen the gap between the enormous knowledge explosion that has occurred over the last couple of decades and scientific achievement. It is not a problem of having inadequate science to do it.

It is a problem of inadequate dollars to get the job done, and the inadequate funding to attract the best and the brightest of the medical schools and graduate programs into scientific investigation.

We think this is the key to this national resource that we've had and we've enjoyed. I think that the perception is very wide—70 percent, expressed in a recent Harris poll—that there is a 30-percent appreciation in the population at large that basic research should be funded by Federal programs in a substantially greater degree.

I think the scope of the problem is quite clear. We know that just diseases of the heart and blood vessels alone will kill more people in 1 year than all other causes of death combined.

I think your rifle company is absolutely a clear reflection of the problem. One-half of all deaths are going to occur from cardiovascular disease. That translates into 1 million deaths a year; and I think the translation into economic burden is in the range of $100 billion.

I think that the fact that we have the NIH and we've been doing superb research has had its impact. We've seen a decline in cardiovascular death in the last decade amounting to about 33 percent.

Now, that's the momentum we're anxious to see maintained and we feel that the proposed President's allocation of 2.2-percent increase for fiscal year 1985—not only does it fall far below that that's been proposed for the other Federal research programs for National Science Foundation, Department of Energy, NASA—they've all ranged between 14 and 18 percent—but we think that it's absolutely critical that the NIH funding be certainly appropriated at about $5.2 billion and that the National Heart, Lung, and Blood Institute should have an appropriation that would reflect nearly a 16-percent increase over last year to maintain the progress in the programs that we have going.

We are concerned that if we don't maintain a well balanced program of research and scientific program demonstration, we're going to fall way behind.

Senator INOUYE. Very good.

Dr. RYAN. It's not just a matter of funding 5,000 new grants. That's the floor. We feel it's critical to maintain well balanced clinical trials, core center grants, and so forth.

So the Heart Association strongly urges this committee to consider this.

Senator INOUYE. I can assure you that this committee is very receptive and very supportive of what you're saying. I'm certain we can find many, many dollars elsewhere that we think are being misspent at this time that can be applied to the activities that you described.

I hope that we'll be successful in that. We'll urge our colleagues to do that.

Dr. RYAN. Thank you, Senator.

Senator INOUYE. Thank you very much.

STATEMENT OF CHARLES F. BARLOW, M.D., CHAIRMAN, MENTAL RETARDATION CENTER DIRECTORS; PROFESSOR OF NEUROLOGY, HARVARD UNIVERSITY; NEUROLOGIST AND CHIEF, CHILDREN'S HOSPITAL IN BOSTON; AND DIRECTOR, CHILDREN'S HOSPITAL MENTAL RETARDATION RESEARCH CENTER

PREPARED STATEMENT

Senator INOUYE. Our next witness is the chairman of mental retardation center directors and professor of neurology at Harvard University, Dr. Charles F. Barlow.

Dr. Barlow, welcome, sir.

Dr. BARLOW. Thank you, Senator Inouye.

In addition I am the neurologist and chief at the Children's Hospital in Boston and director of its Mental Retardation Research Center, one of about a dozen such centers that have been established over the country by Public Law 88-164. This program is administered through NICHD.

In my testimony today I represent those mental retardation research centers and I also believe I speak for mentally retarded people and their families.

[The statement follows:]

STATEMENT OF CHARLES F. BARLOW, M.D.

This statement is prepared in support of the programs of the National Institute of Child Health and Human Development, and especially in support of its programs of research on the causes, prevention and amelioration of the problem of Mental Retardation, and of its research efforts in the relevant related fields of basic developmental neurobiology and neurobiologic research.

The principal focus of research on mental retardation within the NICHD has been a network of Mental Retardation Research Centers which, together with university affiliated clinical training and service facilities, (University Affiliated Programs for the Developmentally Disabled) were constructed as a result of public law 88-164, "The Mental Retardation Facilities in Community Mental Health Centers Construction Act of 1963". As a result of that legislation there were 12 MR Research Centers established, which were located in California, Colorado, Illinois, Kansas, Massachusetts, New York , North Carolina, Ohio, Tennessee, Washington and Wisconsin. The Mental Retardation Research Centers were constructed in the late 1960's and early 1970's with a commitment to a 20-year program of research and training in mental retardation and related aspects of human development. The institutional commitment included matching funds for construction grants, staffing in the form of tenured faculty positions and other supports for the programs of research. Continued federal support has been forthcoming in the form of Core Grants administered by NICHD on competitive peer review plus project and program-project grants that have been awarded by NICHD and other Institutes as well as private foundations.

The essential glue of these Centers has been the system of periodically reviewed Core grants that serve many purposes. From the perspective of the Centers, funding is made available to maintain cost-effective resource laboratories which support common facilities used by many investigators and to effect new initiatives, etc. From the federal perspective the peer-reviewed competing renewal of these Core grants is a system of reviewing the overall scientific excellenceof the research of the centers, the relevance to MR and proper utilization of facilities, collaborative opportunities, etc.

Without the safeguard of overview based on Core grant review, even with the best intentions, there could be some "drift" in the overall excellence or relevance of the centers.

The MR Centers have taken their role as a national network seriously. The directors meet two times per year, usually one time with the U.A.P. colleagues to discuss mutual problems, communicate research progress, etc. For example, the most recent meeting was held in Washington, D.C. in October 1983 where the principal topics for discussion were: a. The current status of the problem of Maternal PKU (phenyl ketonuria). b. New developments in the pharmacotherapy of autism and self-abusive behavior in the retarded and c. Status of Brain Electrical Activity Mapping (BEAM), an advanced computer technique for analyzing brain function.

The national network of MR Research Centers in the aggregate have addressed the broad front of biomedical problems that are the basis of mental retardation in the patient. Another point of emphasis is the behavioral/social/educational research programs which deal with an effort to understand the psychosocial functioning of persons who are already retarded, i.e. to ameliorate the effects of retardation in those individuals who have been affected. Because the work is focused, often collaborative across disciplines and closely related in spirit and function to the training and service facilities (UAP), the results of these efforts is greater than the sum of their parts. The biological approach of the problem has correctly emphasized the understanding of causation and pathogenesis with the aim of prevention because the central nervous system is more refractory than any other tissue in its regenerative capacity. It should be recognized that success in these endeavors will be "invisible" because our patients will tend to disappear. Our national goal, as enunciated in the early 70's by the President's Commission, was that by year 2000 the incidence of mental retardation would be reduced by one half. This goal has not changed.

Nature and Scope of the Problem: Mental retardation is a lifelong problem associated with well over 200 known causes. In a majority of patients the cause is not known and this is the crux of the problem.

Table 1

The following rough diagnostic breakdown of 2,000 patients seen by the Developmental Evaluation Clinic of Children's Hospital, Boston, provided by Dr. Allen Crocker, expresses a fair estimate of the incidence of major diagnostic groupings.

I.	Hereditary issues (inborn metabolic errors, phakomatosis, familial retardation)	4%
II.	Early influences on embryonic development--dysgenesis (sporadic chromosomal abnormalities, multiple congenital anomalies, also includes prenatal infectious processes)	33%
III	Perinatal morbidity (asphyxia, prematurity)	12%
IV.	Acquired childhood diseases (head trauma, meningitis, encephalitis)	4%
V.	Environmental and social problems (psychosocial deprivation, psychosis, and autism)	19%
VI.	Unknown causes (borderline to mild, 2/3; moderate to profound, 1/3; the latter probably including many with cerebral dysgenesis)	28%

Reference: Barlow, C.F. Mental Retardation and Related Disorders, F.A. Davis, Company, Philadelphia, 1978. P4

My colleague at Children's Hospital, Dr. Allen Crocker, who heads our training and service program in MR, has recently reviewed the "state of the art" from the perspective of prevention and has cited 20 activities which can reduce the incidence of MR by 20-30%.*

The principal manifestations of MR are significant impairments to learning, social development and ability to live independently. There are approximately 6,6000,000 retarded persons in the United States today (if the prevalence of mental retardation in the U.S. were the same today as it was in 1970 there would be 7,600,000 mentally retarded persons in our current population, and the difference represents very significant achievement to date). Because mental retardation is a family tragedy and parents and brothers and sisters are impacted, one can estimate that 33,000,000 persons in the American population are touched directly by the problem in their immediate family. The cost in terms of human tragedy can only be fully known by the patients and their families, but it is great.

The economic costs are also staggering. Just to provide for institutionalization of 130,000 retarded persons who must reside in public institutions costs about $3.5 billion per year or an average of $25,000 per person. The cost of educating an educable retarded child to age 21 is more than six times the regular per pupil cost of public education. The only reasonable course is to work as hard as we can to learn to prevent mental retardation as well as to ameliorate its effects when it does occur. These are the goals of the mental retardation community and of the national network of MR Research Centers.

---

*Crocker, A.C., Current Strategies in Prevention of Mental Retardation, Pediatric Annals 11(5):450-457, 1982.

Selected Accomplishments of MR Research Centers in the Immediate Past Year.

Spin-off from the revolution in genetics of the late 70's and 80's have been applied to the problem of MR detection. These include the application of high resolution dye-banding techniques in chromosome analysis, localization of gene sites on chromosomes by hybridization and a thrust to earlier detection of abnormal pregnancies in utero. The important problem of abnormal brain development has been addressed by analysis and identification of the role of certain of the clinical growth factors necessary for maturation. Other recently reported research includes effects of Dilantin and alcohol on the details of brain development, continuing examination of perinatal factors in brain damage, especially in the premature infant. Dr. Baumeister's testimony will deal with the developments in the important fields of behavioral research.

Research Problems of the Present and Immediate Future

1. The highest priority should be placed on better understanding of the basic science of the development and function of the nervous system, (Neurobiology), the causes of abnormal development (Teratology), and the inherited influence on both (Genetics). These areas represent at least 50% of the problem of MR today (See Table 1) and impact on many other birth defects as well. There is an extraordinarily high incidence of mental retardation and other congenital anomalies in the babies of mothers who have treated PKU. The management of such pregnancies is an urgent problem which will be addressed by a multicenter study under the aegis of the Mental Retardation Branch of NICHD that has been approved and hopefully will be funded. This issue also poses an important set of basic neurobiologic questions which can be addressed in the laboratory. For example, do other normal people have an asymptomatic inborn

metabolic error which affects fetal brain development, and where and how does it act?

2. The problem of brain damage in the period around the time of birth, especially the prematurely born, is a continuing challenge for the present and future. With the effective management of the cardiorespiratory system in these tiny babies, a different set of neurological problems have assumed prominence, such as bleeding into the brain cavities, and brain damaging low blood sugar.

3. Behavioral research is faced with the continuing problem of early detection, and of developing educational methods to minimize a handicap related to the degree of disability which range from dyslexia and mild learning problems to the training of the more severely handicapped. The later life management problems of families and the retarded person are continuing issues which involve considerations of residential, work and family placement.

Our recommendations are as follows:

1. Appropriations for NICHD be increased by approximately 10% for fiscal year 1985 (i.e. to $303,000,000) over the $275,000,000 awarded in 1984. According to our understanding the administration request for fiscal 1985 is approximately $280,000,000, a 1.8% increase over the current year. This well below the inflationary decrease in the value of the dollar, and amounts to a vote of no confidence in the efforts to improve the health of our children - the nation's greatest resource for the future.

2. An amount of $9 ,000,000 be identified as a special item for Mental Retardation Research Center (MRRC) core grant support. This level of funding is required for the MRRC's to maintain the momentum of demonstrated effectiveness of these programs to generate information regarding the prevention and amelioration of mental retardation, the leading personal and family tragedy of childhood.

In summary, we need the encouragement and support of the Congress with full recognition that the "blank check" era of research is over. There is no doubt in my own mind that the MR Research Centers represent a collaborative effort of the Universities and the Federal Government that has been a noble, cost effective and successful experiment. They have formed the focus of research attention on a highly significant human problem which has broad biological significance. There has been a measure of success, and I urge that there be continuing support to NICHD and the Centers to enable them to carry out their mission.

Dr. BARLOW. We wish to thank you for that vote of confidence expressed in the fiscal 1984 budget recommendations, but now we must think of fiscal 1985. The manifestations of mental retardation are well known.

There are approximately 6 million retarded persons in the United States today. Because mental retardation is a family tragedy and parents and brothers and sisters are impacted, it is estimated that about 33 million persons in the American population are touched directly by the problem in their immediate family.

The costs in terms of human tragedy can only be fully known by the patients and their families, but it is great. The economic costs are also staggering.

For example, the cost of educating an educable mentally retarded child to age 21 is more than six times the regular pupil cost of public education; and there are many other costs as well. We must learn to prevent mental retardation as well as to ameliorate its effects when it does occur.

Where do we stand today? My colleague at the Children's Hospital, Dr. Allen Crocker who heads our training and service program, NMR or UAP, has recently reviewed the state of the art from the perspective of prevention and has cited 20 activities that can reduce the incidence of MR by 20 to 30 percent. You may be interested to peruse that article.

Senator INOUYE. Would you like this to be made part of the record?

Dr. BARLOW. I think that would be an excellent idea; yes.

Senator INOUYE. Without objection, it will be so done.

[The information follows:]

[Reprinted from Pediatric Annals 11(5) 450–457, 1982]

CURRENT STRATEGIES IN PREVENTION OF MENTAL RETARDATION

(By Allen C. Crocker, M.D.)

INTRODUCTION

During the past 10 to 15 years, there has been a striking growth in interest and concern regarding the systematic prevention of mental retardation and other developmental disabilities. What was formerly a somewhat wistful yearning has become in recent years a major preoccupation of relevant consumer groups, professional societies, and governmental agencies. This new emphasis awaited some of the secondary products of the social revolution in this period, whereby the etiology of developmental handicap was more rigorously examined and codified and there was a cultural commitment to intervene positively regarding factors which compromised human outcome. The efforts to be made were further expedited by results of the surge of biomedical and social research, mostly supported by federal grants, in the post-World War II years. All this provided a technology and a feasibility for effective prevention programs.

KEY PREVENTION STRATEGIES

If one reviews the elements most commonly listed in prevention agendas, whether these are of national or local origin, one notes that a limited (but important) group of resolves appears again and again. The most prominent of these could appropriately be characterized as **"The Golden Twenty"** of the prevention catalogue. These are:

Primary Prevention Activities which are designed to eliminate the occurrence of the condition which causes the handicap.

1) *Rubella immunization* — to prevent the phenomenon of congenital rubella and its attendant morbidity.
2) *Improved prenatal care* — with concern for the pregnancy at risk, including improved nutrition, management of diabetes, and prevention of prematurity.
3) *Special care for the premature infant* — as exemplified by the pediatric specialty of neonatology and the newborn intensive care unit.
4) *Genetic counseling* — for families in which there are known problems (such as Fragile-X syndrome, chromosomal translocations, etc.).
5) *Advice regarding alcohol intake during pregnancy* — for prevention of the fetal alcohol syndrome.
6) *Reduction of environmental exposure to lead in children* — as pertains to both lead intoxication and increased lead burden.
7) *Prevention of kernicterus* — by appropriate Rh-antibody testing and use of immunoglobulin.
8) *Reduction of childhood accidents (head injury)* — by attention to effective restraint in automobiles, and to other hazards.
9) *Counseling and education to reduce pregnancy in the teen years* — with the attendant increased obstetric and social risks.
10) *Efforts to decrease child neglect and abuse* utilizing support, education, and surveillance.
11) *Health and nutrition education* — designed to promote preventive and anticipatory care of children.

Secondary Prevention Activities — in which there is early identification of a relevant condition, and then intervention to avert an outcome with retardation.

12) *Screening of newborn infants for treatable inborn errors of metabolism* — with particular reference to PKU and galactosemia.
13) *Newborn screening for congenital hypothyroidism* — followed by replacement therapy.
14) *Amniocentesis in circumstances of advanced maternal age* — for the prenatal diagnosis of chromosomal disorders (particularly trisomy 21), with a potential for pregnancy interruption.
15) *Screening of maternal serum for elevated alpha-fetoprotein level* -- as an index of neural tube defects.
16) *Carrier identification in genetic conditions* — especially Tay-Sachs disease, to allow counseling regarding pregnancy.

Tertiary Prevention Activities — which bring particular supports to children and families with ascertained problems, to minimize long-term disability and prevent complications.

17) *Early identification, with accompanying intervention and stimulation, in handicaps* — such as deafness or Down's syndrome.
18) *Effective continuing provision of services to families of children with disabilities* — to promote progress of the child and integration of the family.

Basic Activities which Bear on the Ultimate Potential for Success in Prevention Efforts

19) *Continuing research regarding the causation of retardation* — so that a better understanding exists of the contributing factors.

20) *Education of physicians and other professionals* -- regarding the measures available to prevent retardation and disability.

These 20 programs represent the core of the modern prevention scenario, and all or most are commonly represented in the resolves of state agencies and private groups. Actually the potential impact on incidence and prevalence varies greatly among the various components.

DISEASE–SPECIFIC PREVENTION

Particular attention is often granted to some of the disease-specific prevention techniques, since the outcome of these efforts is so concretely perceptible. The technology here is generally a product of molecular or cytogenetic studies, a valuable public application of scientific investigation. A measure of effect can be calculated for these programs, using the reference of a 1:10,000 incidence to represent 0.01% of the new population. In this regard, let us examine the most prominent components, **"The Biomedical Big Six"**:

- Screening for *congenital hypothyroidism.* With a current incidence for this condition of 1:4500 births, with an effective technology, now with all 50 states involved in testing, and with treatment outcomes excellent, one can reasonably claim a prevention effect of only 0.02% or 2 per 10,000 total births.
- Newborn screening for *PKU.* The incidence here is about 1:14,000 (Massachusetts figure), compliance is high and testing efficient, and prevention of retardation by appropriate dietary management can be achieved. The prevention effect then is somewhat below 0.01% or 1 per 10,000 total births.
- Prenatal diagnosis for *Down's syndrome.* Karyotyping of fetal cells to search for trisomy 21 is

generally restricted to pregnancies of women 35 years of age and older, and these women now constitute about 15% of the mothers of new babies with Down's syndrome (overall incidence 1:1000).[1] The percentage of such patients tested has been steadily rising, is now at 25-35%, and may well level off at about 50%. Hence, a reasonable maximal prevention effect of 0.01% or 1 per 10,000 of the total births can be anticipated from amniocentesis.

- Public education regarding *fetal alcohol syndrome*. Current estimate for incidence is about 1:700 births. It is conceivable that vigorous publicity regarding this hazard will eventually reduce its occurrence by half, with an ultimate prevention effect of 0.08% (representing 8 per 10,000 of total births).
- Screening of pregnant women for *neural tube defects* by serum alphafetoprotein (AFP) measurement and followup. Myelodysplasia has an incidence in the United States of about 1:750 births, with approximately two-thirds of the live-born children having significant mental retardation. AFP testing has reached 50% of pregnancies in the United Kingdom, and is much lower here (but could achieve that level), with about 90% effectiveness in detection of the defect. Upon extension of these methods one could hope for a prevention effect of 0.05% (representing 5 cases per 10,000 births).
- Counseling regarding known *genetic diseases*. Guidance to families with Fragile-X syndrome, chromosomal translocations, inborn errors of metabolism (repeat occurrence of pregnancies with children having lipidoses, mucopolysaccharidoses, etc.), and in other unique pedigrees, can impact on the incidence of genetic disorders. Most optimisti-

cally, this could have a prevention effect of 0.01% (representing 1 in 10,000 of the total number of births).

These are active programs, which in the conglomerate might account for prevention of a maximum of 0.18% (18 per 10,000 of total cases) of births with a retardation occurrence. Others can be mentioned in which the natural incidence is sufficiently low that the statistical or public health significance is not oppressive, although the morbidity is compelling. For many of these, the interventions have now had critical value (congenital rubella, kernicterus, Tay-Sachs disease, measles encephalitis). In additional ones the effects of ongoing efforts are not yet known (e.g., children of women with "maternal PKU," campaigns for child restraints in motor vehicles). All of these biomedically-oriented projects clearly cannot affect more than a small portion of the commonly expected 2-3% incidence of mental retardation in the general population.

On the other hand, when one looks at measures available for clinical intervention in the developmental area, it is immediately apparent that truly **"The Big One"** is the improved support now offered for the small premature infant and other troubled newborns. The provision of transportation and centralized intensive care for these at-risk infants has resulted in a simultaneous reduction in mortality and in compromised outcome. This has brought about a relief in developmental morbidity from about 10/1000 to 5/1000 for prematurity, constituting a prevention effect of 0.5% (representing 50 per 10,000 of total births).

It is difficult to quantify the product of other current primary and secondary prevention efforts. Improved prenatal care is certainly significant, as are social programs regarding children's rights and health education. Large elements of the incidence of mental retardation remain incompletely approached by prevention activities, however. These include:

- the vast majority of congenital anomaly syndromes, induced by unidentified prenatal influences
- the majority of occurrences of chromosomal aberrations, including Down's syndrome in children of younger mothers
- causes of encephalitis other than measles
- serious childhood behavioral disturbances and psychosis
- the very important component (one-third of the total) of retardation phenomena in which the causation still remains entirely obscure.

By current technology, we may be able to affect the incidence of perhaps 20-30% of mental retardation circumstances. For the rest, the situation is one of slippage in areas where we have knowledge, and, more importantly, an impact of factors which we can only partially perceive. It is certainly true that relevant social and environmental forces are extant, unfavorable to the hopes of our society regarding childhood outcomes. The challenge here is enormous.

STATE PROGRAMS FOR PREVENTION OF MENTAL RETARDATION

In the United States, it is at the level of individual state planning (departments of public health and/or mental health) where the most vital program development is occurring. Particular leadership in this area has been contributed by California, Indiana, New York, and Virginia. A recent accomplishment of exemplary quality has come from Tennessee, with the report and recommendations of the "Governor's Task Force on Mental Retardation Prevention" (chaired by the Governor's wife, Mrs. Honey Alexander).[2] This group reflected on the status of the field and the circumstances of their state, and brought out conclusions which can serve as a national model. As anticipated, there is a considerable inclusion of elements from **"The Golden Twenty,"** but in a more visionary fashion they reached to broad social supports as central to their effort. The most important recommendations are for:

- access to quality prenatal care for all pregnant women
- family planning services available to every citizen
- family life education in the public schools
- nutritional screening, with supplements as needed to pregnant women and infants
- improved birth certificate information about status of infants
- availability of genetic screening, diagnosis, and counseling
- screening for neural tube defects
- better utilization of regional perinatal care centers, including transport services, physician education, and evaluation
- comprehensive followup of high risk infants, with linkage to appropriate services
- preschool screening of health, vision, hearing, and psychological development
- enhanced immunization programs
- newborn screening and followup for PKU and hypothyroidism
- programs for infant stimulation, parent training, and preschool education for retarded and/or at-risk children under four years of age
- comprehensive, state-wide planning for high risk and handicapped infants
- improvement in "Child Find" efforts

- state oversight of the Head Start Program
- evaluation of the impact of early childhood development programs
- state standards for early childhood education services
- coordination of prevention efforts by the "Children's Services Commission," with continuation of Task Force activities

Of particular note in the Tennessee program are the elements of access, standards, evaluation, and coordination, as well as the generic focus on pregnancy and early childhood as the pivotal periods. The direct involvement of the Governor's office, and the establishment of the follow-up system for the program, are of special value.

Programs like that of Tennessee effectively address the gaps in the more specific conceptual model of prevention (as previously presented). The incompletely identified components in the genesis of retardation stand a significant chance of coverage in a system where support is given to humans in their critical developmental intervals. It is further gratifying that no hesitation is made regarding the provision of activities which could as well be labeled "treatment" as "prevention," in the mode which is implicit in the concept of tertiary prevention. This principle is also emphasized in the recent annual report of the President's Committee on Mental Retardation.[1]

CONCLUSIONS

Activities in the prevention of mental retardation have made substantial gains recently. A solid group of biomedical achievements has served to reduce significantly the incidence or complications of certain serious conditions, but limitations in the understanding of actual causation for many abnormalities places constraints on this approach. For a large portion of developmental handicap the solution presumably rests with more inspired supports to the pregnant woman and the young infant. Joint public and professional planning in this latter area will achieve important results. Further research and professional education are also needed.

REFERENCES

1. Holmes LB. Genetic counseling for the older pregnant woman: New data and questions. New Engl J Med, 298:1-19, 1978.
2. Alexander H et al. *Tomorrow's Children* Governor's Task Force on Mental Retardation Prevention. Tennessee Children's Services Commission, Nashville, TN, 1981.
3. Cohen HJ (ed). *Mental Retardation: Prevention Strategies That Work.* President's Committee on Mental Retardation: Report to the President DHHS Publication No. (OHDS) 80-21029, 1980.

Dr. Barlow. The work is going forward, but much needs to be done. We must learn more about how the brain is put together during intrauterine development and the adverse effects of the genetic and environmental influences that are adverse.

Therein lies 30 to 50 percent of the problem. We must learn more about the factors that injure brains around the time of birth, especially, in the premature baby and there is another 12 to 15 percent of the problem.

Moreover, we must learn to teach the neurologically disabled child so that they may realize their full potential; to understand special problems of the family; and how to manage the best possible adjustment to adult life.

In my own experience, the secret to good adjustment usually lies within the family, but I'm not sure how it happens. We need more systematic information.

My recommendations are that appropriations for NICHD be increased 10 percent for the fiscal 1985 to $303 million; a small vote of confidence in our children. The administration request for fiscal 1985 is $280 million.

Of these funds, we request the following: An amount of $9 million be identified as a special item for the MR center core grant support. The essential glue of these centers has been the system of periodic reviewed core grants which serve to maintain cost-effective resource laboratories, common facilities used by many investigators, and to effect new initiatives in collaborative research.

From the Federal perspective the competing renewal of these core grants is a system of reviewing the overall scientific excellence of the research of the centers and of their relevance to mental retardation. Without this safeguard, based on peer review, even with the best intentions there could be some drift in the overall excellence or relevance.

The national network of MR centers is greater than the sum of its parts. We meet two times per year to compare notes and one of these occasions is a joint meeting with our training inservice colleagues, the UAP directors.

The current issue of the American Journal of Mental Deficiency is devoted to the MR research centers and selected research.

We need your support with full recognition that the blank check era of research is over. The MR research centers represent a collaborative effort of the universities and the Federal Government which has been a cost effective and a successful experiment.

The centers are the focus of research attention to a highly significant human problem that also have broad biological significance. There's been a measure of success; and I urge that there be continuing support to NICHD and to the centers to enable them to carry out their work. Thank you.

Senator INOUYE. Doctor, you've indicated that there are 6 million mentally retarded persons.

Dr. BARLOW. An estimate, Senator.

Senator INOUYE. What is your definition of a mentally retarded person?

Dr. BARLOW. Well, it really has two aspects. One is the intellectual dysfunction, often indicated as an IQ performance ability less than about 70, which is a number; but there also is the important caveat that this relative deficiency in relation to intellectual ability also be accompanied by a disorder of life adjustment.

In other words, social family adjustment is a part of the definition.

Senator INOUYE. We often hear the phrase functionally illiterate.

Dr. BARLOW. Yes.

Senator INOUYE. How would you define that?

Dr. BARLOW. Well, I'm not really certain. I would not use that phrase. I think there are people who have not had the opportunity of an appropriate education; and, on that basis, I think they're regarded as functionally illiterate, that is implying that they could learn to read, could learn to write if given the appropriate educational opportunity.

Senator INOUYE. Now, you spoke of the intellectual deficiency. What percentage does that constitute among the 6 million?

Dr. BARLOW. Well, the 6 million refers to the numbers of people who have an IQ——

Senator INOUYE. Of 70 or less.

Dr. BARLOW. Yes; many of them, the largest number of them probably are in a mildly retarded range. The more significant biomedical etiologies, of which there are many—perhaps 200 has been estimated—usually applies to those individuals who are mentally deficient at a degree of 50 or 60 or less, the severe degrees of handicap.

They are in a trainable group of people as well as people quite totally incapacitated and requiring almost nursing attention for their lifetime.

Senator INOUYE. Many, many years ago when I was an undergraduate I took one of the courses in psychology. At that time, they used phrases such as moron, imbecile, and idiot.

Are these words used now?

Dr. BARLOW. They're part of the history of this field. I think that mental deficiency became a little more specific and usually used, and now people are more comfortable with the term mentally retarded.

The words that you've mentioned are not used. There is an educational conceptualization of trainable, educable, all of which have rather specific meanings; but they're applied more by educators and psychologists these days. The medical definition is the disease if you can identify it.

Senator INOUYE. I'm certain you're aware that this subcommittee is very supportive of you.

Dr. BARLOW. Thank you very much, Senator.

Senator INOUYE. It will continue to be so. Thank you very much.

STATEMENT OF ALFRED A. BAUMEISTER, PH.D., DIRECTOR, JOHN F. KENNEDY CENTER; REPRESENTING AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, AMERICAN ACADEMY ON MENTAL RETARDATION, AND AMERICAN PSYCHOLOGICAL ASSOCIATION

PREPARED STATEMENT

Senator INOUYE. Our next witness is the director of the John F. Kennedy Center, Dr. Alfred A. Baumeister.

Welcome, sir.

Dr. Baumeister.

[The statement follows:]

STATEMENT OF ALFRED A. BAUMEISTER

Mr. Chairman, my name is Alfred Baumeister. I am the Director of the John F. Kennedy Center at Vanderbilt University, one of the 12 national Mental Retardation Research Centers constructed and established under the provision of Public Law 88-164. Appearing here today I represent the American Association on Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association Division on Mental Retardation. These are all professional organizations dedicated to solution of the problems of mental retardation and related disabilities. Speaking on behalf of my many colleagues in these various organizations, I am grateful for the opportunity to share our views concerning federal support, through NICHD, for research on mental retardation and related disabilities.

Mental retardation is a life-long behavioral phenomenon with social, psychological, and biological causes. The principal manifestations are significant impairments to learning, social and physical development, and the ability to live independently. Over 200 different etiologic causes are associated with mental retardation, including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of teratogens, accidents, and other untoward circumstances that affect development, such as extensive poverty, undernutrition, and lack of adequate psychological and social stimulation. Even in many of those cases in which we have some knowledge as to cause, we know little about how to prevent or cure. For the great majority of cases, the causes are not known. It is hard to prevent conditions for which we do not know the causes.

The human and financial costs to society of mental retardation and the other developmental disabilities are staggering. No other human affliction creates so much suffering, for so long, and at such great cost to the individual, the family, the community, and our nation. There are approximately 6,600,000 retarded persons in the United States today and about one out of every 6 or 7 families is directly affected. Just to provide care and habilitation to the 130,000 retarded persons who reside in public institutions, government will spend about $4 billion dollars this year. The average cost to the public is more than $1 million over the life time of each retarded individual. The cost of education of a retarded child in the public schools is about six times the amount expended on the education of a nonretarded child. The variety of special programs in the community that must be provided for our retarded citizens represents an enormous outlay as well. The costs in terms of human suffering and in lost human resources and potential are beyond mathematical calculation. We must remember that mental retardation and the other developmental disabilities, if uncorrected, persist over a life time and that many thousands of babies will be born in this decade who will never have a chance, for even part of their lives, to share in the ordinary opportunities and challenges that we here enjoy. More than that, they will be denied the opportunity to contribute to the commonly shared goals and aspirations of our society.

Despite the enormous complexities that attend the problem of mental retardation, we have made enormous scientific progress over the past two decades toward the twin goals of prevention and amelioration of mental retardation. Much of this knowledge has been put into practice with outstanding results. For example, we now understand the biochemistry underlying some specific genetic disorders and, through proper intervention, are now able to create medical and environmental conditions where these people, who only two decades ago would have been profoundly retarded, are able to live normal lives. Studies of learning processes have enabled us to develop effective educationally based procedures that ameliorate many of the learning and behavior problems associated with mental retardation. We have also learned a great deal more about causes of mental retardation, knowledge that can have enormous significant public policy implications. For instance, we now have convincing experimental and descriptive data showing that alcohol is a teratogen that can have devastating effects on the developing fetus. Public policy has followed from the empirical demonstration that environmental exposure to lead can cause a continuum of biological and behavioral risks ranging from very severe to mild in form.

Over the past few years a variety of exciting new behavioral and biomedical concepts and techniques have been incorporated into the study of mental retardation, such as the role of peptides and neurotransmitters in the functioning of the nervous system, sophisticated quantitative techniques for the study of neuropathology and neuroanatomy, the introduction of new cytogenetic procedures, the discovery of new methods for analysis of plasticity of behavioral development, and new methods for promoting generalized learning and transfer of skills.

These are but a few examples of research-derived technology that has enabled us to understand part of the complex nature of mental retardation and to improve ultimately the lives of many of our citizens while greatly reducing costs to society. Without the continuing support provided by Congress these accomplishments would not have been possible.

Yet, since 1974, the commitment to mental retardation research has deteriorated, and if this trend continues the effects will be extremely serious. Over the past 10 years I have conducted various types of analyses of NICHD funding patterns with particular reference to the status of mental retardation as a funding priority within NICHD. The one general and compelling conclusion emerging from these analyses is that mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with its status 10 years ago. Since 1974, for example, the overall decline in mental retardation research support, expressed as a proportion of the total budget of the Center for Research on Mothers and Children, is almost 20%. In 1984 dollars, our research capability is less than half of what it was in 1974. Core support funding for the 12 national Mental Retardation Research Centers has been severely affected. New programs and new centers, inaugurated without additional appropriations, must inevitably be funded to the detriment of existing programs. Attached is a table that shows a regular and continuing decline in relative support for mental retardation research, from 1972 to 1983.

Last year Congress increased appropriations to NICHD by $20.1 million, or about 8.2% over FY83. However, this was the smallest increase, both in amount and percentage, across the five Institutes that comprise NIH. I have attached a table showing these amounts for FY83 and 84, together with the dollar and percentage increases. Obviously the efforts of the other institutes are important and deserve all the support that Congress can give. But the work of NICHD is no less important to the national well-being.

The Administration budget for FY85 would increase appropriations to NICHD by $5 million, or 1.8%. This is clearly inadequate. We are dealing here with social and medical problems of enormous proportions. To cut back our research capabilities is short-sighted, ultimately very costly, and a grave disservice to millions of American families.

There is another consideration that warrents attention. Research training funds, across the NIH, were held for FY84 to the FY83 level under continuing resolution. In the case of NICHD this amounted to $10.2 million. The Administration would reduce research training funds to $9.8 for FY85. It should be clear to everyone that continued scientific progress against disease and disability depends, in the final analysis, on the efforts of well-trained researchers. In the case of mental retardation, federal support of high-quality research training is especially vital because of the enormous complexities that attend the biological and behavioral conditions associated with mental retardation. This is another situation where short-term and very modest savings will have serious long-term consequences.

Expenditures for research related to mental retardation have declined steadily both in relation to inflation and as a proportion of the relevant program within NICHD. Therefore, our first major purpose is to assure continued support for mental retardation research and to reverse the decline in funding.

We respectfully encourage Congress to increase appropriations to the NICHD to a level that, at the minimum, ensures the continuity of research and research training programs and at a level that begins to reduce the decline in funding for mental retardation research about which we spoke earlier. We believe that this can be done in two ways: (1) provide for an increment in the NICHD budget adequate to offset the effects of inflation and to accelerate the effort in mental retardation research and, (2) more specifically, provide for a meaningful increment in core support for the national Mental Retardation Research Centers.

Our second purpose is to suggest foci of the narrative report language. We believe that improvement of mental retardation services depends on excellent basic behavioral and biological research in the areas of prevention, early diagnosis and intervention, learning, and long-term care. Most important, because mental retardation is a constellation of behavioral phenomena with numerous biological and psychosocial causes, collaborative research programs incorporating behavioral and biological components should be fostered. With these considerations in mind we respectfully make the following specific recommendations:

1. We urge the Congress to increase funding by 10% to the NICHD from $275 million in the current fiscal year to $303 million in fiscal year 1985. This is in contrast to the Administration request for $280 million for fiscal year 1985.

2. That the Mental Retardation Research Centers be designated as a special item in the budget and that $10 million be appropriated for core support for these centers.

3. That the Congress express its commitment to the continuation of high-quality predoctoral and postdoctoral research training by increasing funds in this category by 10%.

Comparative Data Across Institutes*

(Millions of Dollars)

NIH Institute	FY83	FY84	Increase	% Increase
Cancer	962.6	1053.4	90.8	9.4
Heart	595.7	674.7	79.0	13.3
Neurological	287.4	325.5	38.1	13.3
NICHD	244.9	265.0	20.1	8.2
Aging	91.6	112.3	20.7	22.6

*These figures exclude research training funds.

Trends in MR Funding*

(Millions of Dollars)

Year	Total CRMC Funds	Total CRMC-MR	MRDD	MRRC Core
1972	42,838,000	21,365,000	17,250,000	5,856,000
1973	41,971,000	21,330,000	16,642,000	6,533,000
1974	51,894,000	23,886,000	18,096,000	5,761,000
1975	55,094,000	25,420,000	18,884,000	5,672,000
1976	60.161,000	27,016,000	20,423,000	5,608,000
1977	64,979,000	28,419,000	21,434,000	6,166,000
1978	73,790,000	30,298,000	23,318,000	6,455,000
1979	102,492,000	35,321,000	28,121,000	6,759,000
1980	101,154,000	34,731,000	27,559,000	6,751,000
1981	106,055,000	32,997,000	26,969,000	6,623,000
1982	105,530,000	31,768,000	25,963,000	6,549,000
1983	123,346,000	35,270,000	29,306,000	7,343,000
Percents of Total CRMC				
1972		50	40	13.7
1973		51	40	15.6
1974		46	35	11.1
1975		46	34	10.3
1976		45	34	9.3
1977		44	33	9.4
1978		41	32	8.7
1979		34	27	7.0
1980		34	27	6.7
1981		31	25	6.2
1982		30	25	6.2
1983		29	24	6.0

*Source of Data: NICHD, Office of Planning and Evaluation

Dr. BAUMEISTER. My name is Al Baumeister. I represent the American Association on Mental Deficiency, the American Academy on Mental Retardation, and the American Psychological Association. Speaking on behalf of my 100,000 colleagues in these organizations, we are grateful for the opportunity to present our views concerning funding through NICHD for research on mental retardation and related disabilities.

As my colleague, Dr. Barlow, has pointed out there are at least 300, maybe more, different conditions that are associated with mental retardation. These include genetic deviations, problems of pregnancy and birth, brain damage due to a large number of teratogens, accidents and other circumstances such as undernutrition, poverty and lack of adequate social and psychological stimulation.

As an example, we're facing now an epidemic of a condition known as fetal alcohol syndrome. As a Native Alaskan, that's a personal concern to me because the incidence is much higher among certain groups.

I would ask this committee to consider the question as to whether the right of the fetus to a wholesome environment is any less absolute than the right of the parent to behave in ways that jeopardize the development of the baby.

Senator INOUYE. We've been reading about this, but is there any standard that should be applied when a woman becomes pregnant? What should she not do?

Dr. BAUMEISTER. She should not drink.

Senator INOUYE. Period.

Dr. BAUMEISTER. Period. However, I understand that's a very difficult thing to accomplish. In fact, I have recently conducted a survey of prevention programs in all 50 States and there are some good models for identifying high risk parents, families.

I want to emphasize the family because the target of any intervention effort must be the father as well as the mother; but there are some model programs that if adopted on a national scale would greatly reduce the incidence of fetal alcohol syndrome.

When I talk about that syndrome, I am just talking about the extreme case because it follows a dose-response curve such that there are subtle effects of the disease that are not demonstrable except through impairments in learning and so forth.

Senator INOUYE. About what percent of the 6 million that was mentioned would come under this category?

Dr. BAUMEISTER. Well, various estimates that I have attained from the Centers for Disease Control, from the review of the literature, and from my survey of the States place the incidence of fetal alcohol syndrome in its extreme case at about 1.5 or about 1 per 750 births. Among native Americans, it is probably 1.1 to 50; however, that's the extreme case and I'm sure that there are many other instances of fetal alcohol related deficiencies that are just not detected or detectable because they don't express themselves in dismorgenesis.

But there's a large proportion of children who are exposed to various kinds of teratogens that don't include just alcohol, but smoking, other kinds of substance abuse, prescription drugs and so on.

Senator INOUYE. Dangerous business, bringing up children.

Dr. BAUMEISTER. Indeed, it's very difficult, I can assure you.

Despite these various problems, we have made progress toward the twin goals of amelioration and prevention. I want to tell you that our national commitment to mental retardation research has deteriorated.

I have been conducting analyses of funding patterns with NICHD. One compelling conclusion is that mental retardation research is in a much less favorable position today than it was a decade ago. In fact, our research capability is half of what it was in 1974.

Core support for the 12 national mental retardation centers has been severely affected. In my written testimony, I have provided a table that shows that within NICHD mental retardation has been declining as a research priority from 1972 to 1983.

Now, last year Congress increased appropriations to NICHD by $20.1 million, or 8.2 percent, over fiscal year 1983. That was the smallest increase in amount and percentage across the institutes that comprise the NIH.

I've attached another table showing these data for fiscal year 1983 and 1984. The efforts of the other institutes are important and they deserve all the support the Congress can give; but the work of NICHD is no less important to the national wellbeing.

The administration budget for fiscal year 1985 would increase appropriations to NICHD by $5 million, or only 1.8 percent. I think that's clearly indequate.

There's another consideration that warrants attention. Research training funds across NIH were held, for fiscal year 1984, to fiscal year 1983 levels under continuing resolution and I understand part of the problem for that. However, the administration would reduce research training funds within NICHD to $9.8 million over the current $10.2 million.

This is another situation where very short term and very modest savings will have serious long-term consequences. Our specific recommendations, modest as they are, are as follows:

One, we urge the Congress to increase funding by 10 percent to NICHD from $275 million in the current fiscal year to $303 million in fiscal year 1985. This is in contrast to the administration request for $280 million.

Two, that the mental retardation research centers be designated as a special item in the budget and that $10 million be appropriated for core support for these centers. They are the most visible national commitment that we have to solving the problems of mental retardation.

Three, that the Congress express its commitment to the continuation of high quality predoctoral and postdoctoral research training by increasing funds in this category by 10 percent.

I thank you and would be happy to answer any questions you might have.

Senator INOUYE. Well, you're not asking for too much as far as I'm concerned.

Dr. BAUMEISTER. We try to be realistic, Senator.

Senator INOUYE. We'll try to rearrange the priorities. Right now, they're cutting down your program in order that we have funds to pay for the MX missile, but that may change also.

Dr. BAUMEISTER. But if we could just have a Trident submarine to auction off, I think we would solve our problems.

Senator INOUYE. I think so. I agree with you. Thank you very much, sir.

STATEMENT OF ALFRED HEALY M.D., PRESIDENT, AMERICAN ASSOCIATION FOR UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

PREPARED STATEMENT

Senator INOUYE. Our next witness is the president of the American Association for University Affiliated Programs for Persons with Developmental Disabilities; Dr. Alfred Healy.

That's a long title.

[The statement follows:]

STATEMENT OF ALFRED HEALY, M.D.

Mr. Chairman, members of the Committee, my name is Dr. Alfred Healy. I am here today as President of the American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP).

The AAUAP network of 51 university based programs and teaching hospitals participates in several federal initiatives to fulfill its four fold mission. This includes:

- interdisciplinary training of personnel to work with the developmentally disabled,
- exemplary services to this population, their families, and support groups,
- technical assistance, and
- dissemination of promising and proven successful practices.

The AAUAP is a member of the Consortium for Citizens with Developmental Disabilities which has prepared an analysis of the President's Budget Proposals and Recommended Appropriation Levels Relating to Programs for People with Developmental Disabilities. That analysis will be entered separately for the record and has been shared with the staff of the Subcommittee.

Therefore, in the time allocated I will highlight key issues for your consideration.

First, the President's FY 85 request for UAFs funded under the Developmental Disabilities Assistance and Bill of Rights Act would return the ADD funded UAFs to the level of funding prior to the 1981 reductions. While the President's figure of $7.8 million is an increase from the current level of $7.413 million it remains a de facto reduction from earlier levels when inflationary impact is considerd.

The UAF network has struggled to maintain a level of quality while eliminating important services and personnel. This is a result of recent reductions of federal funds. We encourage your support of the $7.8 million as a base level in your deliberations. Further, we wish to emphatically endorse your public acknowledgement earlier this winter that the President's budget remains insufficient to respond to the needs of the Nation's developmentally disabled. The AAUAP is prepared to support and defend funding above the President's budget request to meet the needs of today's beneficiaries and return the commitment of the federal government to the levels of funding anticipated by authorization ceilings in effect before 1981.

In addition, a substantial number of UAFs participate in the fifteen percent (15%) set aside competition within the Maternal and Child Health Block Grant Program. The President's FY 85 request of $407.3 million for the Block Grant Program will remain far short of sufficient revenues to compensate for the reductions incurred in 1981. Therefore, the AAUAP supports an appropriation of $499.5 million for this program. This level will remain short of the purchasing power of the $456.7 million appropriated in 1981, but will reflect a continued committment by Congress to support these vital health services to the pregnant women, infants, children, and adolescents who are the benificiaries. The President has again requested elimination of the 15% set aside component of the MCH Block Grant Program. Already, important services, including UAFs, have experienced approximately forty-five percent (45%) cuts in funds under this program. To eliminate the 15% set aside provision would devastate the critical network of training programs from which we produce physicians, therapists, and other health professionals. Also, access by communities to treatment methods for many developmental disabilities and the application of meaningful research would be lost. For these reasons, the AAUAP strongly urges retention of the 15% set aside program.

Finally, the AAUAP supports an increase in the appropriations for the National Institute of Child Health and Human Development (NICHD). The President's request of $280.2 million represents a 1.8% increase over the FY 84 level. However, it is estimated that an increase of at least six percent (6%) is required just to maintain current levels of service. Among the many important initiatives of the NICHD is the core funding support for 12 mental retardation research centers. These centers and the other NICHD programs have been unable to expand into new areas of study or research training because of insufficient funding. Therefore, the AAUAP supports a FY 85 appropriation level of $319 million for the NICHD program.

Within the FY 85 appropriation level of the NICHD programs it is our recommendation that an amount of $9 million be identified as a special item for the mental retardation reseach center core grant support. If the mental retardation research centers are to be able to continue their mission and further the prevention and elimination of causes and conditions of mental retardation, this level of federal funding and specific acknowledgement of the MRRC program is necessary. In addition, we ask you to pay particular attention to the funding needs of the National Institute of Handicapped Research within the U.S. Department of Education. The NIHR activities work very closely with the research centers under NIH and are important partners in the states and local communities in furthering the habilitation and rehabilitation of the mentally retarded and developmentally disabled into the mainstream of life. Our recommendation of $40 million is equal to the authorization level for the NIHR program and would be money well spent.

Mr. Chairman, members of the Committee, thank you for this opportunity to testify today. We will work closely with your staff in any way which will be helpful to you.

Thank you.

Dr. HEALY. Thank you. I'm pleased to present information to you, Senator. I am Alfred Healy.

I'm a physician in the College of Medicine in the Department of Special Education at the University of Iowa; and I'm here today representing the American Association of University Affiliated Programs which represents 51 UAF's across the country.

We have four Federal missions; that is, providing interdisciplinary training to physicians and therapists and others who provide service, to do that service in an exemplary manner, to provide technical assistance, and to disseminate the results of promising research to those who serve the disabled.

The AAUAP is a member of the Consortium for Citizens with Developmental Disabilities which has prepared an analysis of the President's budget proposals and recommended appropriation levels relating to programs for persons with development disabilities. That analysis will be entered separately and shared with your staff.

First, I'd like to present to you our concerns regarding the President's fiscal year 1985 request for UAF's funded under the Development Disabilities Assistance and Bill of Rights Act. That would return ADD-funded UAF's to the level of funding prior to the 1981 reductions.

While the President's figure of $7.8 million is an increase from the current level of $7.413 million, it remains a de facto reduction from earlier levels when inflationary impact is considered.

The UAF network has struggled to maintain a level of quality while eliminating important services and personnel. This is a result of recent reductions.

We encourage your support of the $7.8 million as a base level in your deliberations. Further, we wish to emphatically endorse your public acknowledgement earlier this winter that the President's budget remains insufficient to respond to the needs of the Nation's developmentally disabled.

The AAUAP is prepared to support and defend funding above the President's budget request to meet the needs of today's beneficiaries and return the commitment of the Federal Government to the levels of funding anticipated by authorization ceilings in effect before 1981.

In addition, a substantial number of UAF's participate in the 15-percent set-aside competition within the Maternal and Child Health Block Grant Program. The President's fiscal year 1985 request of $408.3 million for the Block Grant Program will remain far short of sufficient revenues to compensate for the reductions which occurred in 1981.

Therefore, we support an appropriation of $499.5 million for this program. This level will remain short of the purchasing power of the $406.7 million appropriated in 1981, but will reflect a continued commitment by Congress to support these vital health services to the pregnant women, infants, children, and adolescents who are the beneficiaries of this funding.

The President has again requested elimination of the 15-percent set-aside component of the Maternal and Child Health Block Grant Program. Already important services, including UAF's, have experienced approximately a 45-percent cut in funds under this program.

To eliminate the 15-percent set-aside provision would devastate the critical network of training programs from which we produce physicians, therapists, and other health professionals. Also, access by communities to treatment methods for many developmental disabilities and the application of meaningful research would be lost.

For these reasons, we strongly urge retention of the 15-percent set-aside program.

Finally, the AAUAP supports an increase in the appropriations for the National Institute of Child Health and Human Development, the NICHD. The President's request, at $280.2 million, represents a 1.8-percent increase over the fiscal year 1984 level.

However, it is estimated that an increase of at least 6 percent is required just to maintain current levels of service.

Among the many important initiatives of the NICHD is the core funding support for 12 mental retardation centers, which you just heard Dr. Barlow present. These centers and the other NICHD programs have been unable to expand into new areas of study or research or training because of insufficient funding.

Therefore, the AAUAP supports a fiscal year 1985 appropriation level of $319 million for the NICHD program.

Within the fiscal year 1985 appropriation level of the NICHD program, it is our recommendation that an amount of $9 million be identified as a special item for the Mental Retardation Research Center core grant support. If the mental retardation research centers are to be able to continue their mission and further the prevention and elimination of causes and conditions of mental retardation, this level of Federal funding and specific acknowledgment of the MRRC Program is necessary.

In addition, we ask you to pay particular attention to the funding needs of the National Institute of Handicapped Research within the U.S. Department of Education. The NIHR activities work very closely with the research centers under NIH and are an important partner in the States and local communities in furthering the habilitation and rehabilitation of the mentally retarded and developmentally disabled into the mainstream of life.

Our recommendation of $40 million is equal to the authorization level for the NIHR program and we would encourage it as being money well spent.

Mr. Chairman and Senator Inouye, we thank you for this opportunity to testify and stand ready to answer questions.

Senator INOUYE. Well, Doctor, you're very fortunate. You have sitting before you the real savior and hero of health research and health care in this country, and in this Congress especially.

I have just one question for the record because people have asked: What is your definition of developmentally disabled?

Dr. HEALY. A developmental disabled person is one who has experienced a significant problem in their developmental process prior to the age of 22; and that that problem interferes significantly with their life function and it interferes with their ability to lead independent lives and to operate and function within society as contributing children and adults.

Most of them are medically represented as having cerebral palsy, mental retardation, autism, or epilepsy or seizure disorders.

Senator INOUYE. So it covers everything.

Dr. HEALY. To a certain degree, it does, sir; but one of the major implications in the Federal definition is that the causation appear prior to the age of 22.

Senator INOUYE. Why 22? I'm just curious.

Dr. HEALY. That is a time period after which most of the developmental aspects of the person's life have already occurred. That is the growing period of a person's life.

After that, they are pretty well set in their life.

Senator INOUYE. Thank you very much.

Senator WEICKER [presiding]. Thank you very much, Dr. Healy, and thank you very much, Senator Inouye.

Dr. HEALY. My pleasure.

Senator WEICKER. Dr. Blair Batson, chairman of the Department of Pediatrics, University of Mississippi. Dr. Batson.

STATEMENT OF BLAIR E. BATSON, M.D., CHAIRMAN, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF MISSISSIPPI MEDICAL CENTER

Dr. BATSON. Senator Weicker. I'm Dr. Blair Batson, a pediatrician at the University of Mississippi Medical Center, and I am representing today the American Academy of Pediatrics.

I am pleased to comment today on four major areas which impact on mothers and children—the maternal and child health block grant, research, the Immunization Program, and primary care training in pediatrics.

I am here as a voice for our Nation's children, who have obviously been shortchanged in this time of tight fiscal policies. Our children do not come first in our Nation's priorities. Since 1980, $1 of every $10 previously provided them for critical preventive and health maintenance programs has been lost.

Specifically, we're recommending a funding level of $499 million for the MCH block grant. Legislation is currently pending to increase the authorization to accommodate this amount.

Very simply put, 47 States have reported cutbacks in services, eligibility or both, at a time when there is an increased demand for services. Indeed, as much as sixfold increase in some areas. While States attempt to focus on those with the greatest need, the impact of budgetary cutbacks falls on the working poor, the moderately handicapped, and the recently unemployed.

From California's experience with proposition 13, reductions in prenatal care and well-child care can be anticipated, and an increase in the associated morbidity that comes with such reductions.

Second, we would call your attention to the critical need for significant commitment to biomedical research sponsored by the NIH. The academy joined a number of other health groups in support of a 16-percent increase in total funding for NIH. Of the moneys allocated, we are requesting a level of $330 million for NICHD, the primary institute aimed at preventing death, disease, and disability.

The point, again, for the low ranking of children in national priorities, the NICHD was allocated the lowest percent increase in the President's budget of all the institutes at NIH.

While there are no instant breakthroughs to cope with the variety of problems that affect children and their families, there are promising advances in need of support.

One area that has been severely neglected is the need for NICHD to take the lead in expanding and coordinating injury research and development, with the emphasis on the preventing of accidents and injuries. Trauma, in fact, represents the largest loss of potential years of life and burdens the Nation with enormous costs, in terms of pain and suffering and disability, loss productivity, and medical services. Injuries are the leading cause of death and disability in all age groups from 1 year to 40.

I ask you, why is that there has been no national focus on research in prevention in this area? We would urge that this committee specify this initiative in its report. Such an initiative may be compared, in terms of lives saved and function preserved with the assault on infectious diseases of a generation ago.

Senator WEICKER. What particular initiative are you referring to?

Dr. BATSON. On injuries and accidents as a cause of death and disability, and also with a real new initiative, in terms of study of how do we prevent, what can we do to prevent the most common cause of death and disability from age 1 year to 40 years of life.

I do not need to remind the committee of the cost effectiveness of the Childhood Immunization Program.

We are requesting a funding level of $54 million for fiscal 1985. These moneys will be targeted at the administration's initiative to eliminate rubella, German measles, the Government purchase of DPT vaccine under its consolidated contract abilities, and in providing for adequate stockpile of vaccine. The cost of vaccines have dramatically been increasing.

Finally, we're requesting $18 million for primary care training, an essentially no-growth budget from fiscal 1984.

In our training programs of today, we must prepare pediatricians for tomorrow, a time of dramatic changes in child health needs. The basic training programs must continue to be modified to enable pediatricians to meet the increasing demand for their services in the areas of adolescent medicine, learning disabilities, development and psychosocial and biosocial problems.

Modest Federal support must be continued to assist us in responding to this dramatic shift in educational needs.

You know, we Americans love to talk about progress, improving the quality of life, in meeting the challenges of tomorrow. All of these depend on our ability to create an environment and to provide the service which will enable today's children to grow up with healthy minds and bodies.

Thank you, sir.

PREPARED STATEMENT

Senator WEICKER. Thank you, Dr. Batson. We will insert your statement in the record at this point.

[The statement follows:]

STATEMENT OF BLAIR E. BATSON, M.D.

Although the President's fiscal 1985 budget for the Department of Health and Human Services proposes some slight increases and reductions of lesser magnitude compared with previous years, it continues a downward trend in the support of health programs, particularly as they apply to maternal and child health. Our children obviously do not come first in our nation's priorities, having lost since 1980 one of every 10 dollars previously provided them for critical preventive and health maintenance programs. If indeed a federal budget serves to reflect the priorities of this nation, mothers and children rank shamefully low. It is interesting to note that the increase proposed by the fiscal 1985 defense spending authority is greater than the total allocated for Medicaid and the Public Health Services programs.

MATERNAL AND CHILD HEALTH BLOCK GRANT -- $499 million

Since enactment, the American Academy of Pediatrics has reviewed some 20 articles, studies and reports on the maternal and child health block grant. The questions addressed in these studies relate to the impact of the federal regulatory changes, to the federal funding cuts, and to how states respond to the new flexibility reflected in the law. To summarize, the studies have found that when comparing the last year of the categorical grant system with the first year of the maternal and child health block grant:

- Few states have changed the types of programs offered;
- Most states have initiated new restrictive eligibility requirements and/or reduced services;
- Programs with a statewide emphasis, ones historically having state fiscal participation, and those with a vocal constituency continue to receive support under the block grants;
- Most states have made across-the-board funding cuts in all programs;
- Most states have not added state money to replace lost federal money;
- Some states have used carry-over funds from the previous year to lessen the impact of the federal budget cuts.

In FY81, the total appropriation for the programs consolidated into the maternal and child health block grant was $456,896,882. Just to stay even, adjustments for inflation using the Consumer Price Index (CPI) would add an additional 10.4 percent increase for 1981, a 6.1 percent increase for 1982 and a 4 percent increase for 1983, for a total funding figure of $556,590,758. Bear in mind this increase is based solely on the CPI and does not reflect the increased cost in medical care, which amounted to 11.6 percent between 1981 and 1982. For fiscal year 1984, Congress has funded the maternal and child health block grant at $399 million, or a 28 percent reduction in funding had the programs remained categorical (including an inflation factor). Specifically for FY84, maternal and child health was increased by $26 million or 6.9 percent. However, if one takes into account the special supplemental funding of $105 million for FY83, the FY84 appropriation for maternal and child health was decreased by $79 million, or 16.5 percent, the largest cut in funding for all the health block grants.

In 1985, we can anticipate program changes in many states, given the decreasing amount of funding. Preliminary information seems to indicate that states will favor broadly targeted programs and those historically receiving state funds. Most states list services for crippled children as a top priority. It appears that other programs focusing on sudden infant death syndrome, genetics, hemophilia and lead-paint poisoning, or programs designed to meet needs of the inner-city poor may not fare as well.

Even though the studies show that in most states the same services are being provided, people in need of maternal and child health services will not receive them. Forty-seven states have reported cutbacks either in services, eligibility, or both. Also some states have imposed fees. States are also experiencing an increased demand for services under the maternal and child health block grant. This derives from a decrease in Medicaid funding and services and from loss of private health insurance due to unemployment. Maternal and child health directors report seeing more referrals for the "near" poor, as much as a sixfold increase in some areas.

It is difficult to assess the complete impact of the funding cuts on people and services because existing baseline data are poor, and future data will not be comparable due to changes in the reporting system. The states focus on serving those with the greatest need; thus the impact of reduced services will most likely fall on the recently unemployed, the working poor or the moderately handicapped. Tragically, recent reports have been made of increased infant mortality in some states indicating areas of compromised services. Furthermore, if one projects from California's experience with Proposition 13, reductions in prenatal care, family planning, well-child care and immunization programs can be anticipated as well as the associated morbidity that comes with such reductions.

Legislation is currently pending in both the Senate and House to increase the authorization for the maternal and child health block grant to $499.5 million. As a minimum, an appropriation of $483 million is needed just to stay even with inflation. We would urge, however, that the figure of $499 million be allocated to assure program standards and accessibility.

RESEARCH -- NICHD $330 million

The Administration has requested an increase of $89 million or approximately 2 percent, less than the projected rate of inflation. This would result in a decrease in our biomedical research efforts. The Academy has joined with many other health organizations urging a 16 percent increase in the total funding for NIH. We would take this opportunity to reiterate that support and also to address the specific needs of NICHD.

Again to point to the low ranking of children in national priorities, NICHD was allocated the lowest percent increase of all the Institutes at NIH. At a time of shrinking budgets, it is appalling to slight the Institute directed at preventing disability and death during the critical period surrounding infancy and during the ensuing childhood years. Research devoted to controlling diseases of infancy, diseases which all to often leave their victims handicapped for life, contributes mightily to one of the chief goals of medical science -- prevention. Even beyond the obvious human grounds on which increased funding for NICHD can be based, there are substantial savings to be had. Prevention of these major disorders, which could save billions of dollars in treatment, hospitalization and loss of work time, depends on efforts focused on early life. There are no instant breakthroughs to cope with these age-old problems that afflict children and their families, but there are promising advances. They must be spurred.

The Academy recommends a funding level of $330 million for fiscal 1985. These monies should be targeted at the following:

- funding of 750 competing research project grants (approximately 50 percent of estimated approved research project grant applications);
- an initiative directed at the prevention of low birthweight, a critical problem impacting on this nation's standing with respect to infant mortality and morbidity rates;
- studies directed at treating or preventing abnormal human development;
- studies directed at behavioral and biological predictors of mental retardation, behavioral markers of genetic syndromes and developmental neurobiology;
- funding of 2 additional research centers in the areas of fetal growth and growth factors and perinatal pharmacology;
- contraceptive development and contraceptive evaluation;
- a new initiative directed at reducing the toll of injuries in childhood -- the leading cause of death and disability in childhood and young adults.

I would like to expand on the latter initiative and to highlight the urgency of this request. Trauma represents the largest loss of potential years of life and burdens the nation with enormous costs in terms of human suffering and disability, lost productivity and medical services. NICHD should take the lead in expanding and coordinating trauma research and development in at least the following areas:

1. Epidemiologic research is needed on the distribution of injurious death and disability from various causes and in various subgroups of the population (defined by geography, age, race, sex and socioeconomic status).
2. Biomechanical research is needed on the effects of transfer of various types of energy to various sized human bodies in various situations, e.g., using anthropometric childhood dummies to study the effects of various types of trauma on the bones and soft tissues of children. This information will significantly advance the understanding of both inflicted and unintentional injuries.
3. Research is needed on injury-promoting behavior, i.e., the children's behaviors that put them in danger of injury, and the adults' behaviors that fail to protect the children from injuries (inflicted and unintentional).
4. Devices and programs that interfere with the transfer of injurious forms of energy to childhood victims at the various points at which intervention is possible need to be developed.

Such an initiative may be compared -- in terms of lives saved and function preserved -- with the assault on infectious diseases a generation ago.

CHILDHOOD IMMUNIZATIONS -- $54 million

One of the best examples of an effective preventive measure is childhood immunization. It is one program which experts accept as a safe and cost-effective expenditure. Immunization against seven childhood diseases -- diphtheria, pertussis, tetanus, measles, rubella, mumps and polio -- has been responsible for a reduction in childhood mortality and the handicapping conditions which can result from these diseases. The 3 million children born each year must be immunized against these diseases; each failure becomes a potential victim for the future.

In the mid-1960s it became evident that immunizations could play an important role in child health. In 1966 the federal government began to fund measles and polio immunization programs through grants to states. In 1977 the federal government launched a major drive, the Childhood Immunization Initiative. This program provided matching grants to states to 1) purchase vaccine; 2) inform parents of the need for immunization; and 3) assess the number of children protected. This highly successful program was greatly responsible for raising the immunization levels of kindergarten and first-grade children to more than 95 percent in 1983.

The rising financial cost of these programs, both federal and state, must be met. The failure to provide adequate funding means significant cuts in services. The Center for Disease Control and other public health experts warn that within one year after relaxing immunization programs, the rise of reported cases of measles, rubella, polio, diphtheria, pertussis and tetanus would result in needless tragedy. No one can quantify the pain associated with these illnesses. Deafness, blindness, cerebral palsy, retardation and severe emotional disturbances can destroy children and their families. When the capacity to prevent these conditions is at hand, failure to protect our citizens is doubly cruel.

The Academy recommends a funding level of $54 million for fiscal 1985. This slight increase would include monies for the following:

- an Administration initiative to eliminate rubella;
- government purchase of DPT vaccine under its consolidated contract which currently includes only purchase of polio and MMR vaccines. DPT costs have increased dramatically over the last year and states have been saddled with an economic burden which poses a serious threat to the immunization program;
- providing adequate funds for the vaccine stockpile.

PRIMARY CARE TRAINING -- $18 million

The need for adequate support is pressing. Advances in prevention and control of traditional acute and infectious diseases permit the pediatrician to devote more time and attention to what have been relatively neglected areas: chronic disease; the increasing number of behavioral problems of childhood and adolescence; and what we call biosocial problems, those health problems socially induced or complicated by social and environmental factors. Because coping with the challenges of modern society will cause an increase in the incidence of biosocial problems, modern pediatric training must be directed more specifically to the treatment of those problems.

There has been also a dramatic increase in our recognition of child health problems associated with poverty, a deteriorating physical environment, changing family structures and other social and psychological factors. There is growing evidence that encouragement of health promotion and changes in life-styles may become more important than medical intervention in affecting morbidity and mortality. The pediatric community recognizes that pediatric education must respond to these changes in child health needs. We ask Congress to follow suit by authorizing the funds to allow us to develop and maintain an educational program relevant to those needs.

In the future, pediatricians will be called upon more and more to manage children with emotional disturbances, learning disabilities, chronic illnesses and other problems of a developmental, psychological and social nature. They will provide increased amounts of health care to adolescents. They will be expected to manage their practices efficiently, collaborate with other members of the health care team and use community resources to enhance the effectiveness of services to children and their families.

The ambulatory experience responds to these needs by developing skills in counseling, anticipatory guidance, developmental appraisal, referral, consultation, use of screening procedures and practice management. Skills relating to the care of children with chronic illnesses and handicapping conditions are particularly important. Finally, the ability to coordinate services, plan comprehensive care and mobilize available community resources is essential to provide ambulatory care of high quality. To accomplish all this, there remains a distinct need for faculty development and greater support for research related to ambulatory care. Full-time faculty members in ambulatory pediatrics need formal training in the discipline; it is no longer acceptable to assume that any pediatrician can teach ambulatory pediatrics.

Unfortunately, the pediatric community finds itself in the unenviable position of responding to a dramatic shift in educational need in an atmosphere of fiscal restraint. Moreover, increasingly larger percentages of medical school funds are being devoted to the delivery of patient care, a development which we recognize is a justified response to the public demand for quality health but one which means that other sources of support are necessary if service programs in educational centers are to improve the teaching environment -- particularly through the development of model ambulatory care programs. An appropriate program of grants for general pediatric training could respond to this need by earmarking funds for the development of ambulatory pediatric models.

The Academy is familiar with recent reports which question the need for the training of new physicians. While we continue to asses this issue ourselves, we are requesting a funding level of $18 million for pediatric and internal medicine training programs, essentially the same amount in the fiscal 1984 appropriation.

We thank you for your consideration.

Senator WEICKER. I couldn't agree with you more, and I might add, that this is a part of our society we neglect. It used to be that we were supposed to live for our children. This is the first element of society we forget nowadays in the quest for our own comfort, our own needs and our own expediency, politically and in every other sense of the word.

So I can assure you we will take a close look at your remarks.

Also, I might add, the matter of the vaccine was mentioned by several witnesses yesterday. I think you can rely on the committee to bring forth a proper funding level for that. At the same time, I would like to know why these vaccines have increased so dramatically in the last 3 years?

Dr. BATSON. We'll try to get that information for you.

Senator WEICKER. Thank you.

Dr. BATSON. Thank you, sir.

PREPARED STATEMENTS

Senator WEICKER. Your statement will be included in the record at this point as well as other statements submitted on the budget for the National Institute of Child Health and Human Development.

[The statements follow:]

Letter From Milton Markowitz, M.D., Professor of Pediatrics, Associate Dean for Student Affairs, the University of Connecticut

April 16, 1984

The Honorable Lowell P. Weicker, Jr.
Chairman
Subcommittee on Labor, Health and
Human Services, Education and
Related Agencies
Committee on Appropriation
United States Senate
Washington, D.C. 20510

Dear Senator Weicker:

I regret that I was unable to testify before your Committee. However, I would like the enclosed document included in the record. The initiative aimed at reducing infant mortality as outlined in the document is extremely important. We need only to be reminded that the infant mortality in the capitol city of our State is higher than that in many developing countries.

Sincerely yours,

Milton Markowitz

Milton Markowitz, M.D.
Professor of Pediatrics
Associate Dean for Student Affairs

Statement of Milton Markowitz

Mr. Chairman and members of the Committee, I would like to take this opportunity to offer my comments on proposed funding for child health research under the Fiscal Year 1985 budget. I offer this statement as a pediatrician and Professor of Pediatrics at the University of Connecticut Medical Center in Farmington, Connecticut.

Having examined the budget justifications to this Committee by the Director of the National Institute of Child Health and Human Development, I feel compelled to express my support for the Institute's research program in general, and for one proposed major research initiative in particular. At the same time, I must strongly object to the relatively low funding level requested for this important work.

Mr. Chairman, we in the United States have not reached the point where we can be complacent about our nation's infant mortality. Yet, this is what the Administration budget request is saying in effect. I would urge you to change that message. In the area of child health research, we stand at an important crossroads where new medical opportunities exist. If we are farsighted, we can take advantage of recent developments. We can make strides in improving our country's infant survivability and, in doing so, help assure for each child born the opportunity for a healthy life.

Despite all of our medical and technological advances, today the United States still ranks 17th in the world in terms of infant mortality. At the same time, we can say that the care a premature or low birthweight infant receives in this country is probably better than it would receive anywhere else in the world and dramatic drops in infant mortality have occurred over the past decade. While this may seem like a paradox, it is not. The discrepancy occurs in the fact that more premature and low birthweight babies are born in this country than anywhere else in the world. Over the past two decades, U.S. infant mortality has dropped by 50 percent but the number of premature or low birthweight infants born has hardly changed. And it is these infants who have the greatest struggle and face the highest chances of death or a lifelong disability.

Fully two-thirds of all infant mortality occurs among babies considered to be low in birthweight. This condition also accounts for three-fourths of all infant deaths during the first 28 days. These infants are abnormally small because their growth was retarded in the womb. They face higher than normal risks of suffering from a wide range of health problems at and after birth. Obviously, the smaller the baby, the greater the risk. Most mortality occurs among infants weighing under 3 1/2 pounds. Each year in the U.S. 50,000 of these tiny babies are born, while another 200,000 are born weighing less than 5 1/2 pounds, the common cutoff point when discussing low birthweight for a fullterm newborn. In all, 8.5 percent of all births produce low birthweight infants. Of those low birthweight infants who survive, many suffer handicaps such as mental retardation, cerebral palsy, seizures, learning problems, blindness and deafness. Unfortunately, these handicaps are usually non-reversible and the victim spends a lifetime coping with the particular handicap. In fact, the incidence of such handicaps in very low birthweight infants, those under 3 1/2 pounds, may be as high as 60 to 70 per cent at school age.

In economic terms the cost is enormous for both the individual and the nation. The annual cost of newborn hospital care alone for low birthweight babies is $2 billion. These infants require extra treatment and long periods of neonatal intensive care, especially the babies under 3 1/2 pounds. This figure does not include costs for physician services and lifelong treatment of handicaps.

It is important to point out that low birthweight may be due to either intrauterine growth retardation (IUGR) or premature birth. Of course, it is also possible for a baby to be both early and small for gestational age, further complicating the treatment process.

Our current inability to predict which babies will be born too small is one of the major problems in the effort to understand and eventually prevent low birthweight. This issue was discussed at a recent research planning workshop on intrauterine growth retardation sponsored by the National Institute of Child Health and Human Development. At least half of the growth retarded babies born today follow pregnancies during which there was no reason to suspect problems. Certain conditions in the fetus such as dwarfism, brittle bone disease and some chromosome abnormalities are known to cause retarded prenatal growth. But researchers believe it is more a case of the mother's genetics and environment that may be behind the problem in most instances. Only in the past decade have studies been able to distinguish consistently between infants that are premature and those that are born growth retarded. In other related areas of research, discoveries in the last few years have provided several promising leads on the mechansim that starts labor. Newer imaging techniques involving ultrasound and nuclear magnetic resonance (NMR) offer potential for better prenatal diagnosis of the low birthweight condition.

Mr. Chairman, it appears that the time is right to take advantage of these and other developments with a concerted research program. As I mentioned earlier, the seriousness of this problem warrants our complete effort. And the state of the science in this field holds the potential for major advances in understanding and eliminating low birthweight as a major cause of infant mortality.

The National Institute of Child Health and Human Development has recognized this opportunity, as evidenced by the Institute's proposal to launch a major new initiative on the prevention of low birthweight. Although the Institute already supports a broad research program in this area --in fact many of the recent research advances came from NICHD grantees -- the new initiative would greatly enhance this effort. The initiative would focus on the two areas that contribute the largest number of infants to the low birthweight population: intrauterine growth retardation and premature labor.

Several targeted research efforts would be part of this new initiative. One area of study involves fetal growth factors. A number of substances have been identified that act on various aspects of growth. These substances include nerve growth factor, growth hormone and epidermal growth factor, to name a few. Virtually nothing is known about how these substances affect growth of the fetus, or their possible role in intrauterine growth retardation. With new immunologic techniques it is now possible to develop antibodies specific for each of these growth factors, administer the antibody in pregnancy, and assess the effect on fetal growth.

Another effort would focus on biological predictors of fetal growth. A number of biological measurements have been suggested by scientists, but so far there has not been adequate assessment of each to determine its value and effectiveness in predicting a low birthweight delivery. There are suggestions that indexes such as blood volume and certain plasma hormones may be valuable and good methods of assessment are now available. To test these possible predictive indexes will require large clinical studies.

The new initiative would examine perinatal pharmacology and toxicology because it has been recognized that the fetus and the low birthweight infant are exposed to many medications. Drugs have been shown to cause an effect on the fetus and some may be of long-lasting consequences. Advances in prenatal diagnosis and the use of drugs to treat specific fetal and neonatal problems carry the responsibility of understanding drug-fetus interactions at the time of administration and immediate or long-term consequences. The NICHD proposal would involve the establishment of a Perinatal Emphasis Research Center on Perinatal Pharmacology and Toxicology to provide a coordinated research effort in this field.

Another study would examine the biochemistry of labor. While we know what starts labor in sheep, we still do not know what triggers the start of labor in humans. Finding this trigger should give us clues on how to stop premature labor once it starts, or better yet, prevent it from starting. Scientists are coming closer to understanding the biochemical events that make up labor. Unfortunately, many of the animal models developed thus far have proved not to apply to the human situation. Micromeasurement techniques are now being used to find the labor trigger by searching for signals from the fetus, from stress or from other sources such as microorganisms that may be responsible. Just this year, an NICHD supported researcher isolated a substance in fetal urine which may be the key to discovering this elusive trigger. In another development, the Institute has begun a multi-center clinical trial seeking to identify specific types of infection of the maternal genitourinary tract that may increase the risk of premature birth. Then, through antibiotic treatment of such infections, an attempt will be made to reduce the preterm birth rate. The new initiative also will include research into the mechanism that is responsible for the premature rupture of membranes. Such investigation and development of ways to diagnose these events would enable preventive measures and appropriate management to be applied earlier than is currently possible in pregnancies now.

To help facilitate clinical trial work and the development of new therapies in this initiative, the NICHD would establish a network of leading obstetric maternal-fetal medicine units that care for women at high risk of having a low birthweight baby. This network would then provide enough patients so that important clinical questions could be asked and answered quickly. Other parts of the Institute would conduct targeted information and education efforts involving high-risk women and practicing physicians. Still other efforts would involve joint projects with other institutions such as the Ford Foundation, Robert Wood Foundation, the Institute of Medicine or the March of Dimes.

To help coordinate the initiative, the Institute would create a National Low Birthweight Prevention Advisory Committee. This group would provide advice on planning, developing and evaluating all aspects of the new program.

Mr. Chairman, let me conclude by again emphasizing the importance with which the pediatric and obstetric community views the NICHD research program in general. In particular, we feel that this proposal for a major initiative on low birthweight is timely and deals with the most important problems regarding the special health concerns of mothers, infants and children. In contrast, however, the requested budget of $280,178,000 will not do justice to the opportunities to gain new knowledge in science and in health, and to support the cadre of scientists upon whose productivity we depend. When the problems of infant mortality are so great, how can we afford to pay only 28 percent of approved research project grant applications? When we still don't know what starts labor and the birth process, how can we effectively cut the funding of research centers by holding their support at last year's level? When the best leaders in academic medicine attest to the need for young scientists with new ideas, why do we reduce our investment in research training programs?

For these kinds of reasons, Mr. Chairman, the amount made available to the NICHD must be increased well above the President's budget to some $330 million. With this level of support, we would see 50 percent of approved research projects being funded; new initiatives started in such areas as low birth weight, mental retardation, and learning disabilities; and an infusion into the research community of the numbers and kinds of young scientists who have been so important to our progress in the past. This funding level is a very realistic expectation, Mr. Chairman. And that kind of investment in the NICHD programs will reflect the value this nation places on giving each child the opportunity to be as healthy as possible and to develop to his or her greatest potential.

STATEMENT OF DR. ROBERT BRENT, CHAIRMAN, DEPARTMENT OF PEDIATRICS, JEFFERSON MEDICAL COLLEGE, PHILADELPHIA

I am Dr. Robert Brent, and as Chairman of the Department of Pediatrics at Jefferson Medical college in Philadelphia, I have a special interest in birth defects, the leading cause of infant death in the U.S. My statement here on behalf of the National Institute of Child Health and Human Development, therefore, reflects a clinician's appreciation of the need to improve the knowledge base about the causes, treatment, and prevention of birth defects.

Clinicians generally define birth defects as structural or functional abnormalities that originate before birth and interfere with physical well-being. Approximately three percent of infants have major birth defects diagnosed at birth, and another four percent have abnormalities detected in the months and years after birth. This adds up to more than 250,000 infants in the U.S. who are born with physical or mental defects each year.

Birth defects are costly, both emotionally and financially, for the individuals who have them, their families, and society. The emotional toll is incalculable. The financial toll is in the range of more than $1 billion a year spent by society and individuals for state services, hospital stays, and private physician visits to treat birth defects. The total financial burden is actually much greater.

All of this underscores the need to develop better treatments for individuals with birth defects, and the even more pressing goal of preventing birth defects in the future. Progress has been made on both fronts, but innumerable challenges remain.

In the area of treatment of birth defects, research has recently brought some innovative approaches. For example, scientists at NICHD are in the process of testing an experimental treatment they have discovered for Hurler's syndrome. Children with this genetic disorder lack an essential enzyme and, as a result, suffer dwarfism, enlarged organs, and a variety of other complications that usually cause death during childhood. The researchers will try to replace the missing enzyme by transplanting amnionic membrane tissue under the abdominal skin of the patient. The tissue, which can be obtained during casarean deliveries, is not rejected by the child's immune system. Over the next year, the researchers will follow the 14 children who have received implants to see how long the implanted tissue survives and how much of the missing enzyme is produced.

New approaches to treating birth defects have extended into territory previously untouched--the prenatal period. Drug therapy and surgery have been performed in humans and animals before birth. Although fetal drug therapy is a new area of research, studies show promising results. Researchers have succeeded in preventing several biochemical and developmental disorders in newborns by treating them before birth, through administration of various drugs, vitamins, and nutritional regimens to pregnant women. NICHD scientists have performed fetal surgery in animal experiments, and several physicians, not affiliated with the NIH, have operated on human fetuses and succeeded in correcting certain developmental abnormalities.

While these advances in treatment are important, the ultimate goal of research on birth defects is prevention. Before steps can be taken toward prevention, however, the causes of birth defects must be understood. There are two general categories of birth defects: those that have a genetic basis involving abnormal genes or chromosomes; and those that are caused by nonhereditary factors, such as mental disease, infection, malnutrition, mechanical constraint, or exposure to teratogenic doses of radiation, certain drugs or chemicals. At NICHD, both genetic and nonhereditary causes of birth defects are under study.

In efforts to understand the basis for disorders caused by genetic defects, scientists funded by NICHD have achieved several advances in gene transfer research. In these experiments, researchers have succeeded in transferring genes to mice from other animals. The "foreign" genes function in the mice and are passed on to their offspring. These animal models are invaluable tools for studying how genes are turned on and off, and will give clues as to how genes guide the differentiation of countless cells into specialized tissues during development. Moreover, with continued research, the gene transfer technique could ultimatrely lead to cures for many genetic diseases and to the prevention of the diseases in future generations.

Discoveries in the past several decades have brought insights into many nonhereditary causes of birth defects. We now know that the fetus is vulnerable to external causes of maldevelopment, including drugs taken by the mother during pregnancy, with thalidomide as the prime example; maternal illness such as diabetes mellitus; various infections including rubella and cytomegalovirus; and ionizing radiation. These findings have led to many preventive measures, such as the vaccine rubella, special prenatal care for diabetic mothers, and warnings to pregnant women to avoid drugs and other environmental or life-style factors that could cause birth defects.

Despite progress in this area, the causes of the majority of birth defects are still unknown. An important goal of the NICHD is to determine these causes through basic and applied research of normal and abnormal development. This program will continue to exist with current funding levels. New initiatives must be taken, however, and new leads that are uncovered by basic research must be followed, if we wish to take an aggressive approach toward identifying the unknown causes of birth defects. This means more resources are needed.

The fiscal resources available for NICHD's programs, therefore, must be discussed along with the scientific priorities. As a figure for the entire Institute, the requested budgetof $280,178,000 simply will not do it. Throughout the pediatric research community, the NICHD would strive for a funding rate that will recognize at least half of the scientists whose research project grants are approved for funding. We ask for full funding of approved research grants, without the gamesmanship of negotiated reductions below already austere budgets. We say at least maintain the number of research traineeships, don't cut them.

We implore you to remember the special contribution of networks of research centers whose interdisciplinary contributions add so much more to the research effort. Above all,. Mr. Chairman, we ask that you look at these mechanisms for the support of research enterprise in terms of the health problems that they address--not only birth defects, but also mental retardation, high risk pregnancy and infancy, and child growth and development. I have discussed the needs in just one of these important areas, and strongly recommend that the appropriation be raised above the nominal increase proposed by the Administration. Based on identified needs and readiness of the research community to respond, our judgment is that a total of some $330,000,000 is most reasosnable for this Institute. This is our investment in the future health of our country, our most valuable natural resourse, the childiren of the next generation.

Senator WEICKER. I am going to use my prerogative, because I have to leave at 11:45. Senator Burdick will then preside over the hearing.

Is Elva Busch here? I just wanted to alert her—she's not here yet. All right. Well, then, let's proceed to the next session, the Health Resources and Services Administration. Janet Stern, the executive director of the South-West Community Health Center of Bridgeport, CT.

STATEMENT OF JANET STERN, EXECUTIVE DIRECTOR, SOUTH-WEST NEIGHBORHOOD HEALTH CENTER, BRIDGEPORT, CT

PREPARED STATEMENT

Senator WEICKER. Welcome, Janet.

Ms. STERN. Thank you, and good morning.

Senator WEICKER. Good morning. We will insert your statement in the record before you proceed.

[The statement follows:]

STATEMENT OF JANET STERN

My name is Janet Skane Stern, Executive Director of the South-West Neighborhood Health Center in Bridgeport, Connecticut, and I am speaking on behalf of the National Association of Community Health Centers which represents more than 800 community-based, public and private nonprofit Community, Migrant and Urban Indian Health Centers throughout our Nation. As you know, these centers provide basic health care to America's poorest, most disadvantaged people from inner-city ghettos and urban Indian neighborhoods to rural migrant farmworker labor camps and isolated, resource-poor communities.

I deeply appreciate the opportunity to discuss with you today the problems which these health centers face in the current economic climate, and the issues of fiscal 1985 funding for the federal programs which support the health center activities. I also wish to address some very serious concerns we have with a number of recent federal policy decisions which affect the operation of the health centers.

Overview of Health Centers

Health centers supported through the primary care program authorities have proven to be effective and efficient providers of quality health care to some five million Americans, most of whom have no other available source of care. These include medically (and, often, economically) indigent persons who lack public or private coverage -- including large numbers of the currently unemployed -- as well as Medicare and Medicaid recipients refused care by other private providers (often because of low payment rates or discriminatory practices). In many rural communities, these centers are the only available health care providers for miles. Despite these difficulties and the generally poor health of their patients, the primary care centers have been effective health care providers, according to findings in an overwhelming majority of independent studies over the past decade.

- They have provided continuous, high-quality health care to their patients, and have increased the use of preventive services (such as immunizations and pap smears).
- They have reduced illness and hospitalization rates among their patients (by as much as 50 percent for comparable populations), and yet have held down their costs to a level con-

siderably lower than for other health care providers, which results in tax savings.

These health centers do not interfere with or duplicate the efforts of other private practice providers, but are located in areas where there is a shortage of personal health services. Thus, their role is both appropriate and vitally necessary. The federal support (both grant funding and placement of health professionals through the NHSC) received by the health centers is used solely to subsidize the cost of care for indigent, uninsured and underinsured persons to cover the cost of non-reimbursable services such as preventive service and health education, and to establish the capacity for the delivery of health service in such areas. In effect, the health centers serve to insure their local communities against the cost of care for the uninsured; even if other providers were available to serve these persons, the cost of their care would have to be met through increased taxes.

Funding History Summary

As a result of the Reconciliation Act reductions of fiscal 1982, federal support was terminated to 284 centers and some 300,000 people. In addition, service reductions occurred in most of the remaining 587 centers.

As a result of your leadership, Mr. Chairman, and with strong support by many on this Committee, restorations were made for both Community and Migrant Health Centers in fiscal 1982, 1983 and 1984. While some of the centers are at or near previous (FY-81) operating levels, the vast majority are not, because virtually all of the "new" dollars were for "new" initiatives or activities such as Health Promotion/Disease Prevention, NHSC conversions, and new starts. While we are most supportive of these activities, the fact remains that base grants to existing centers have been held constant for over four years, while centers have been faced with increased patient loads, increased costs, high unemployment, and reductions in Medicaid and Medicare. The attached table depicts a complete funding history (FY 79-84) regarding Community Health Center appropriations.

Let me cite some statistics which illustrate this point.

- Between 1974 and 1981, centers increased patient loads by 300 percent, while federal grant funding increased by only 65 percent.

- Between fiscal 1981 and 1982, while 284 Community Health Centers were defunded, the patient load increased by over 30 percent.
- Between 1979 and 1984, the average base grant to existing CHCs has dropped from $434,000 to $428,000 in actual dollars, a loss of 1.4 percent.
- In real dollars (corrected for inflation), the average CHC base grant has dropped from $434,000 to $299,000, a loss of 31.1 percent, over the same period.
- In order to maintain the 1979 level of services, the average CHC base grant would have to be: $622,000 in 1984; $649,000 in 1985.
- To achieve those base grant levels, the Congressional appropriation for the CHC program would have to be: $388 million for 1984; $405 million for 1985 (assuming the total appropriation was used solely to fund basic CHC services, i.e., no new starts).

It is important to point out that the Senate, through report language in S. Rept. 98-247, recognized this situation and, with respect to additional funding, prioritized the adjustment of base grants before "new" activities were commenced. Unfortunately, this language was not picked up in the conference report -- and was conveniently ignored by the Department of Health and Human Services.

Recommendations

I. Community Health Centers - $370 million

This amount would retain current services only. Currently, the CHC funding is being used to subsidize the NHSC field program. The Department indicates it will reprogram $10 million in fiscal 1984 and request an additional $10 million in fiscal 1985 for conversion of NHSC obligees from federal-salaried to CHC grant-hire physicians. This would add $20 million to the 1984 level of $337 million -- $357 in total. The Administration is requesting $7 million for inflation (about 2 percent). In light of the fact that CHC base grants have not been adjusted in over four years to help offset increased costs and patient loads, we are requesting $13 million to adjust base awards (3.9 percent), totalling $370 million.

II. Migrant Health - $50.8 million

This amount is $8.8 million over the fiscal 1984 level and about $6.8 million over the Administration's request. While Congress did approve limited restorations in FY 1984, this program is still operating at $2 million below the FY 1981 level. Similar to CHCs, Migrant Centers will increase patient loads by 60,000 in FY 1984 (up 15 percent). As a result of the 1982 reductions, services at the 128 centers were cut drastically. We are requesting $4 million additional funding to restore services ($2 million) and to adjust base grants at existing centers by 4.8 percent ($2 million) to cover increased costs and patient loads. We are requesting an additional $4.8 million to expand services such as outreach to labor camps, environmental services, parasitic screening, and restorative dental services through existing centers. It should be noted that after 22 years, this program still serves less than 15 percent of the eligible migrant and seasonal farmworker population.

III. National Health Service Corps

A. Scholarship - $8.6 million. This would provide support to the current 50 students in the pipeline and provide support for 500 new scholarships, which we recommend for three years. The Administration has once again requested zero.

B. Field Program - $91.9 million. This amount would support 1,580 field assignees in fiscal 1985. Of the remaining 2,003 health professionals, 1,217 would be picked up under the CHC program, leaving 786 private practice option placements. This coupled with the CHC recommendation makes much more sense and better utility of the NHSC than the Administration's ridiculously low request of $67 million.

IV. Program Support, Bureau of Health Care Delivery and Assistance - $43.0 million

BHCDA program support has been and continues to be an essential part of effective program management. The tremendous successes of health centers and the Corps is due in no small part to this effort. The Administration has requested $21.8 million, a reduction of current staffing by 425. This request assumes passage of a new Primary Care Block Grant which Congress has rejected in each of the past three years.

Mr. Chairman, we appreciate your concern and tremendous efforts to support effective and efficient programs. I would be happy to answer any questions.

ATTACHMENT

COMPARISON OF BASE FUNDING LEVELS FOR CHCs
FY 1979 - FY 1984

($ in millions)

	FY1979	FY1980	FY1981	FY1982	FY1983	FY1984
Appropriation	$258.9	$320.0	$325.0	$282.3	$360.0	$337.0
Earmarked Funds (Total)	2.5	54.4	8.2	24.3	108.6	54.7
• Evaluation, T.A.	(2.5)	(4.2)	(3.2)	(2.6)	(4.1)	(3.8)
• HP/DP	--	--	--	(10.2)	(10.5)	--
• Phase-Out	--	--	--	(11.5)	--	--
• New Starts	--	(50.2)	(5.0)	--	(12.0)	(15.0)
• Shared Services	--	--	--	--	(2.0)	(1.9)
• NHSC Conversion	--	--	--	--	(15.0)	(18.0)
• Jobs Bill	--	--	--	--	(65.0)	(10.0)
• Migrant Transfer	--	--	--	--	--	(4.0)
• Aging Initiative	--	--	--	--	--	(2.0)
Base Funding	256.4	265.6	316.8	258.0	251.4	282.3 (267.3)**
Continuing Projects	591	632	736	587*	587*	624*
Average Base Grant ($000)	434	420	430	439*	428*	455* (428)**
• In 1979 ($000)***	434	389	365	340	312	318 (299)**

* - The actual number of grantees was: FY82 - 550; FY83 - 550; FY84 - 587. However, of the 186 grantees terminated in FY82, 37 were merged with other existing grantees (i.e., their grant funds were given to the other grantees to enable a continuation of services to their patients). Therefore, for purposes of comparison, the 37 grantees were included in the FY82-84 figures.

** - These figures exclude the $15 million in FY84 funds earmarked for continuation of NHSC assignees converted in FY83 (the $18 million shown for NHSC conversions in FY84 is for additional conversions).

*** - Using GNP Deflators as follows: 1979 - 8.1%; 1980 - 9.0%; 1981 - 9.7%; 1982 - 6.0%; 1983 - 4.6%; 1984 - 4.7%. Source: CBO. (Actual for 1979-1982; estimates for 1983-1984.)

Ms. Stern. I am Janet Skane Stern, and I am the executive director of the South-West Community Health Center in Bridgeport, CT. I am speaking on behalf of the National Association of Community Health Centers, which represents more than 800 community based public and private nonprofit community, migrant and urban health—and urban Indian health centers throughout the United States. As you know, these centers provide basic health care to America's poorest, most disadvantaged people from inner-city ghettos, rural migrant farm worker labor camps, and isolated, resource-poor communities.

The people that we serve are the people who are poor, the people who are near-poor with no insurance coverage. We serve the unemployed and medicaid recipients, and we are seeing probably the bulk of the medicaid recipients, particularly in the States where medicaid reimbursement is so very, very poor and the private sector will not accept the low rates. And Connecticut is one of those States. Less and less doctors and dentists are accepting medicaid.

I am deeply grateful and appreciate the opportunity to discuss with you today the problems which health centers face in the current economic climate and the issues of fiscal 1985 funding for the Federal programs which support the health center activities.

As a result of the Reconciliation Act reductions of fiscal 1982, Federal support was terminated to 284 centers, and some 300,000 people were without care. In addition, service reductions occurred in most of the remaining 587 centers, my center included in that number.

Because of your leadership, Senator Weicker, and with strong support by many of this committee, restorations were made for both community and migrant health centers in fiscal 1982, 1983, and 1984.

While some of the centers are at or near fiscal year 1981 operating levels, the vast majority are not. This is true, because virtually all of the new dollars were for new initiatives or activities, such as health promotion, disease prevention, National Health Service Corps conversions, and new starts.

Just to cite an example, at my health center, we do have National Health Service Corps people. I was given $30,000 to cover this physician in internal medicine, his salary. I had to take $12,000 out of my operational budget to take care of his fringe benefits and, of course, the malpractice that we must have in order for him to work and to admit patients to the hospital.

While we are most supportive of these activities, the fact remains that base grants to existing centers have been held constant for over 4 years, yet centers have been faced with increased patients loads, increased costs, high unemployment, and reductions in medicaid and medicare.

Just to break that down a little bit. I've already explained that the medicaid reimbursement in the State of Connecticut is atrociously low and in many other States. I believe New Jersey is just about at the same level as Connecticut. Within the service area that the health center provides services, the unemployment rate is in and around 45 percent. Health center users have doubled. We don't have the moneys to provide services for the people who need the services. And as a result, people are being treated, and we are not being reimbursed. The money has got to come from somewhere, and it's coming from the 330 moneys that are my base grant. And I know that this is peculiar to a great many health centers in the United States, not just mine.

I have attached a table with my statement which depicts a complete funding history from 1979 to 1984, regarding community health center appropriations.

Let me cite some statistics which illustrate this point. Between 1974 and 1981, centers increased patient loads by 300 percent, while Federal grant funding increased only by 65 percent. Between fiscal years 1982 and 1983, patient loads increased by 30 percent. In the highly populated inner cities, health centers have doubled the double of users. We have to use jobs bills moneys to meet the shortfall, as well as to take care of the people for whom this money has been appropriated, namely, the unemployed.

Between 1979 and 1984, the average base grant to existing community health centers has dropped from $434,000 to $428,000 in actual dollars, a loss of 1.4 percent. In real dollars, corrected for inflation, the average community health center base grant has dropped from $434,000 to $299,000, a loss of 31.1 percent over the same period. I'd like to reinforce the fact that we are only requesting a 3.9 increase. In order to maintain the 1979 level of services, the average community health center base grant would have to be $622,000 in 1984 and $649,000 in 1985. To achieve those base grant levels, the congressional appropriations for the Community Health Centers Program would have to be $388 million in 1984 and $405 million in 1985.

The figures I have just mentioned assumes the total appropriation to be used solely to fund basic community health center services, meaning no new starts. It is important to point out that this committee through report language accompanying last year's Health and Human Services appropriations bill, recognized this situation, and with respect to additional funding, prioritized the adjustment of base grants before new activities commence. Unfortunately, this language was not picked up in the conference report and was conveniently ignored by the Department of Health and Human Services.

Senator WEICKER. Janet, I must be fair to everyone else concerned; we are a few minutes over your time, and I don't want anyone to say, "Well, he treats his friends from Connecticut, the voters one way, and the rest of us another way." Therefore, we will include the rest of your statement in the record at this point.

Now tell me, in terms of actual persons, how many people does your health center service today.

Ms. STERN. OK. We're talking about at least 5 million people.

Senator WEICKER. No; I'm talking about your particular center in Bridgeport.

Ms. STERN. My health center has an enrollment of 10,000 people.

Senator WEICKER. How many did it have 2 years ago?

Ms. STERN. Two years ago, it had 5,000 people.

Senator WEICKER. Two years ago, what did you receive in Federal funds?

Ms. STERN. I received the same as I got last year.

Senator WEICKER. In other words, it's been level-funded?

Ms. STERN. Yes.

Senator WEICKER. In this period——

Ms. STERN. I have never gotten an increase.

Senator WEICKER. Those that you serve have doubled?

Ms. STERN. Yes.

Senator WEICKER. And yet the moneys are the same?

Ms. STERN. That's right. I have never gotten an increase, since we were first funded in 1977.

Senator WEICKER. Well, then, what happens to these people? If you've doubled the number of people served—in effect, what do they get?

Ms. STERN. Well, we've had to cut back on our services.

Senator WEICKER [continuing]. A quick look-see? Under those circumstances, I don't see what can be really delivered.

Ms. STERN. Yes; we are delivering primary care services, but we have had to cut back on other service.

Senator WEICKER. Now was this supposed to have been covered by one of the block grants? Does anybody know? In other words, the State of Connecticut is supposed to make up the shortfall, do you know?

My question is, has anybody made up for this shortfall?

Ms. STERN. No.

Senator WEICKER. No.

Ms. STERN. No. No; we've had to cut back on our services.

Senator WEICKER. All right. As I said, we will accept your statement in its entirety in the record at this point. And I thank you very much for your testimony.

Ms. STERN. I thank you very much—even though you didn't give me enough time. [Laughter.]

Senator WEICKER. Now, I think everybody in this room will judge that the chairman was more than fair, because they all have their testimony too. [Laughter.]

Ms. STERN. Wonderful.

Senator WEICKER. And I don't want to be unfair to everybody else. We can't exploit a hometown advantage, in other words. [Laughter.]

Is Elva Busch here? Elva, why don't you come up and testify. As I said, Senator Burdick is going to be taking over in a few minutes, and I want to at least cover those that do come from my home State.

STATEMENT OF ELVA BUSCH, PRESIDENT, CONNECTICUT ASSOCIATION OF HOME ANESTHETISTS

Ms. BUSCH. I'm also from Connecticut, and I'll try to be brief.

I'm Elva Busch, a certified registered nurse anesthetist. I am the immediate past president of the Connecticut Association of Nurse Anesthetists, and I am a faculty member of the New Britain School of Nurse Anesthesia in New Britain, CT.

I would like to thank the committee and particularly the chairman for their support of nurse anesthesia programs. And I am also thankful for having this opportunity to give testimony here today.

My testimony is to justify an expanded budget for the Nurse Anesthesia Training Program authorized under section 831 of the Public Health Service Act over the current level of $400,000.

I am testifying on behalf of the American Association of Nurse Anesthetists, which is a professional organization of 22,000 certified registered nurse anesthetists or CRNA's.

PREPARED STATEMENT

With your permission, we'll also be submitting our testimony to the record, to which I will be referring.

[The statement follows:]

STATEMENT OF ELVA BUSCH

INTRODUCTION

This testimony is provided on behalf of the American Association of Nurse Anesthetists (AANA), a professional organization of some 22,000 Certified Registered Nurse Anesthetists, (CRNA), who perform over 50% of the anesthetics in this country.

I am Elva Busch, Immediate-Past President of the Connecticut Association of Nurse Anesthetists and a faculty member of the New Britain School of Nurse Anesthesia in New Britain, Connecticut.

PURPOSE OF TESTIMONY

The purpose of this testimony is to justify an expanded budget for the nurse anesthesia training program authorized under Section 831 of the Public Health Service Act over the current level of $400,000.

DESCRIPTION OF CRNAs

Certified Registered Nurse Anesthetists (CRNA), are licensed professional nurses who have qualified themselves through academic and clinical achievements. In order to be a CRNA, one must:

1. Graduate from an approved program of nurse anesthesia accredited by the Council on Accreditation of Nurse Anesthesia Educational Programs/Schools, hereinafter referred to as the Council on Accreditation;
2. Pass the Certification Examination which confers eligibility for certification by the Council on Certification of Nurse Anesthetists; and
3. Be recertified every two years by the Council on Recertification of Nurse Anesthetists.

Attachment 1 includes the general requirements required for graduation from an accredited nurse anesthesia educational program.

Nurses have been administering anesthesia in the United States for close to a century. The specialty of nurse anesthesia emerged prior to World War I and nurse anesthetists have functioned with distinction in both civilian and military settings. The practice of CRNAs is legally sanctioned in all states and other legal jurisdictions of the United States. They function as employees of hospitals, employees of physicians, as members of the federal services, or as independent contractors with patients and/or hospitals.

CRNAs are recognized in a variety of federal programs, such as (1) the Civilian Health and Medical Program for the Uniformed Services (CHAMPUS); (2) the Federal Employee Health Benefits Program (FEHBP); (3) the Medicare Conditions of Participation; (4) Joint

Commission on the Accreditation of Hospitals (JCAH) standards; and (5) the Medicaid program. In fact, eight states permit direct reimbursement of CRNAs under Medicaid. In addition, twenty-four Blue Cross/Blue Shield plans, representing over thirty percent of all such plans, directly reimburse CRNAs. Of private insurance plans surveyed by the AANA, fifty-seven percent indicate that they can provide direct reimbursement to CRNAs for anesthesia services.

JUSTIFICATION FOR CONTINUED SUPPORT

The need for continued support for nurse anesthesia education can be justified for a variety of reasons. These follow.

1. FEDERAL STUDIES REGARDING SUPPLY AND DEMAND

The demand for nurse anesthesia services has been demonstrated in a variety of studies. According to a 1977 HEW study, the projected need for CRNAs ranged between 22,267 and 25,530 for 1980. Currently there are 18,955 active-practicing CRNAs, and this produces a shortfall of from 3,312 to 6,575 compared to what was needed in 1980. SEE NOTE 1. More recent studies on related matters generally confirm those data. With the disturbing drop in the number of nurse anesthesia education programs, we are only producing approximately 1200 new graduates each year. Since our specialty is some ninety years old, our attrition from the ranks of active practice approximates 700 per year - from retirement, death, disability or other causes. Thus, our net gain per year is only about 500 new CRNAs.

The increasing age of the American public will also contribute to an increased demand for anesthesia providers in the coming years. The Census Bureau projects that elderly Americans will double in number between the years 1980 and 2020, and that by the year 2030 one in every five people will be at least 65 years old. The average life expectancy for those people born in 1982 is 74.5 years, according to the National Center for Health Statistics. This type of information points to an increased need for CRNAs in the future. As the average life expectancy increases, the percentage of the elderly population will also increase.It can be expected that this will result in an increase in numbers of surgical procedures as well as their complexity.

The Institute of Medicine - National Academy of Science report entitled "Nursing and Nursing Education" recommended: "The federal government should expand its support of fellowships, loans, and programs at the graduate level to assist in increasing the rate of growth in the number of nurses with master's and doctoral degrees in nursing and relevant disciplines. More such nurses are needed to fill positions in administration and management of clinical services and of health care institutions, in academic nursing (teaching, research, and practice), and in clinical specialty practice." Nurse anesthetists were one of the groups specifically addressed in this report.

2. QUALITY/COST EFFECTIVENESS

Research studies have demonstrated that there is no significant difference in the outcomes of care for anesthetics administered by CRNAs and anesthesiologists. SEE NOTE 2.

Nurse anesthesia affords the means to moderate the escalation of costs associated with the provision of anesthesia services. Today, the median income of anesthesiologists, the medical specialist in this field, is reported to be $150,000 whereas the gross mean income of CRNAs in 1982 is reported as $36,748. SEE NOTE 3.

3. COST OF NURSE ANESTHESIA EDUCATION

The cost of nurse anesthesia education is escalating because of a variety of reasons: (1) the inability of hospitals to fiscally support this educational endeavor to the extent it has in the past; (2) the movement of these educational programs into academic settings at the graduate level; and (3) the length of programs ranging from 24-30 calendar months. The increased cost of nurse anesthesia education had been a major reason for the decrease in nurse anesthesia education programs over the past decade by one-third, i.e. from 213 to 137. Prior to the mid-seventies, students often received stipends and tuition assistance from hospitals. However, with the increasing cost constraints placed on hospitals, this support has all but dried up.

4. LACK OF OTHER AVAILABLE FINANCING SOURCES

The nature of nurse anesthesia education does not lend itself to part-time study and part-time work because the classroom and clinical commitment requires approximately sixty-fours hours per week. It is essential to complete this curriculum since certification in this specialty is required for entry into practice.

Most of the programs funded under the Nurse Training Act do not apply to nurse anesthesia educational programs, making the Nurse Anesthestist Traineeship Program essential to this nursing specialty. The first funding of this program in Fiscal Year 1984, although modest in amount, has been helpful but requires expansion if nurse anesthesia is to fulfill its commitment to society in the future.

In summary, there is a present need estimated for about 6000 additional nurse anesthetists. There is reason to believe the demand and need will increase. Student financial assistance is critical to enable nurses to complete the nurse anesthesia educational program. The rapid advances in knowledge and technology mandate a continuous upgrading of educational programs to meet the demands of the increased complexity of anesthesia care, serving as the basis for our request for expanding the Nurse Anesthetist Traineeship Program.

BUDGET REQUEST

SECTION 831 (a)

The AANA is requesting continuation of the Nurse Anesthetist Traineeship program and an increase in dollars appropriated and authorized for it. The Fiscal Year 1984 authorization for this program was $800,000, while $400,000 was appropriated to it. We are requesting that this program be expanded as follows:

Fiscal Year	# Students Assisted	Requested Funding
1985	200	$1.0 million
1986	350	$1.7 million
1987	500	$2.5 million

The monies requested are based on an assumption of providing $5,000 per traineeship.

The current nurse anesthetist traineeship program criteria follow. In order for the program to be eligible to receive grant monies for its students, it must be accredited by the Council on Accreditation and have an eligible applicant currently enrolled, i.e., a student with a baccalaureate degree. This is consistent with the upcoming change in the Council on Accreditation's Standards which will mandate this requirement for admission to accredited programs in 1987.

The Division of Nursing will then distribute the appropriated funds to the programs on a per eligible applicant basis. The program will retain the ability to distribute the funds to its students who have completed at least twelve months of nurse anesthesia education within the constraints of Division's criteria.

SECTION 831(b)

The AANA has presented to the Senate Labor and Human Resources Committee a request for an amendment to Section 831 for Fiscal Years 1985, 1986 and 1987, which would provide authority for funding faculty development grants for nurse anesthesia educational programs. Funding requests for this expansion of the Nurse Anesthetist Traineeship Program would result in grants to educational institutions which would be used to provide stipends and tuition assistance to CRNAs actively engaged in nurse anesthesia education in pursuing master's and doctoral level education. The justification for this request is based on the crucial need for academically credentialed faculty appropriate to the level of the program conducted both within the academic and clinical settings. This need has been caused by the rapid movement of nurse anesthesia education into graduate programs within colleges and universities. By 1987, all accredited nurse anesthesia educational programs will be post-baccalaureate in nature.

The funding requested is based on the assumption that master's level grants would amount to approximately $7,000 per year for two years, while doctoral grants would amount to $9,000 per year for three years. The funding based on the number of grants requested for faculty development is as follows:

Fiscal Year	# Students Assisted		Requested Funding
1985	Master's	20	$230,000
	Doctoral	10	
1986	Master's	40	$460,000
	Doctoral	20	
1987	Master's	40	$550,000
	Doctoral	30	

While the amounts of money requested may be modest for accomplishing the purpose cited, individual CRNAs have made graduate education a matter of priority and others would if their individual responsibilities would only permit. Thus, it is our belief that this small number of grants would permit some outstanding CRNAs to pursue such education who could not otherwise afford graduate education. Suggested language for amending Section 831 is found in Attachment 2.

SUMMARY

In summary, the AANA is requesting a budget for Section 831 for Fiscal Year 1985 to include funding for selected traineeships for nurses seeking to become nurse anesthetists and for selected CRNAs pursuing graduate study at the master's and doctoral level. The total funding requested for this program is as follows:

Fiscal Year 85 - $1.2 million.
Fiscal Year 86 - $2.2 million.
Fiscal Year 86 - $3.0 million.

We thank the Committee for this opportunity to present this testimony and request. We view this proposal as an opportunity for the federal government to invest in a venture which can be demonstrated to have a long term cost-effective benefit in the provision of quality anesthesia services to this country. We believe the returns on such an investment should not, indeed cannot be ignored if health care costs are to be contained without decreasing the services provided to the American people.

NOTES TO TESTIMONY ON
THE APPROPRIATION FOR
THE NURSE ANESTHETIST TRAINEESHIP PROGRAM

Note 1: Documentation of Demand for CRNA Services may be found in the following:

Deaprtment of Health Education and Welfare, "Supply, Need and Distribution of Anesthesiologists and Nurse Anesthetists in the U.S., 1972 and 1980", Reference No. HRA 77-31, 1976.

Institute of Medicine - National Academy of Science Study, "Nursing and Nursing Education": Reported 1983.

Note 2: Quality of Anesthesia Care and Research Documentation

Bechtoldt, A., et al, "Committee on Anesthesia Study, Anesthesia Related Deaths, 1969-1976", North Carolina Medical Journal, 42:4 (April, 1981.)

Hirsch, R.A., et al, Health Care Delivery in Anesthesia, (Chapter 15: Forrest, W. "Outcome--The Effect of the Provider" and Chapter 16: Gilbert, J. "Outcome--Experience and Training of the Anesthetist") Philadelphia: George F. Strickley Co., 1980.

Note 3: Cost-Effectiveness of CRNAs

The large differential in income between nurse anesthetists and anesthesiologists, particularly in light of the research findings demonstrating comparable outcomes of care demonstrates the cost-effectiveness of CRNAs. The latest available figures pertaining to the earnings of anesthesiologists were reported in USA Today, November 22, 1983, in which a survey conducted by the Roth Young Personnel Service was utilized. This survey indicated that anesthesiologists were the fastest growing and highest paid medical specialist in the United States, having a median annual income of $150,200. The range of income reported was from $77,500 to $250,000. In the most recent survey conducted in the fall of 1983, previously cited in this testimony, gross mean earnings reported by CRNAs for 1982 were $36,748.

From this data, it is evident that anesthesiologist earnings are approximately four times that of nurse anesthetists and few, if any of the arguments medicine has traditionally used to justify the great spread between their earnings and those of nurses, between anesthesiologists and nurse anesthetists, can be justified. An article which has looked at these arguments and failed to find justification for them is from the September, 1982 Harper's Magazine by David Osborne, entitled "Rich Doctors, Poor Nurses".

ATTACHMENT 1

COUNCIL ON ACCREDITATION OF NURSE ANESTHESIA EDUCATIONAL PROGRAMS/SCHOOLS

STANDARDS AND GUIDELINES FOR THE ACCREDITATION OF NURSE ANESTHESIA EDUCATIONAL PROGRAMS/SCHOOLS, 1980

(Excerpted from pages 14-22)

B. General Requirements:

1. The length of the program shall be a minimum of 24 months.

2. The minimum number of anesthetics administered by each student shall be 450 for a minimum of 800 hours of actual anesthesia time.

3. Minimum requirement for didactic instruction is 425 contact hours. (50 minutes = one class hour.)

4. Time activity design shall include a master class schedule reflecting the sequence of subjects, and the distribution of both class hours and clinical

practice hours per specified period of the program. (A sample master class schedule is enclosed in the Appendices.)

C. Minimum Competencies Required of New Graduates of Nurse Anesthesia Educational Programs/Schools:

Competence is defined to include knowledge, judgment, skills and attitudes appropriate to the accomplishment of anesthesia care goals while affording patient safety in the performance of the function.

1. Perform a preanesthetic interview and physical assessment.

2. Evaluate patient history, physical and appropriate lab and x-ray data.

3. Develop an appropriate anesthesia care plan consistent with the overall medical and nursing regimen.

4. Perform general anesthesia for all ages and all categories of patients utilizing a broad variety of techniques and agents. (Experience in anesthesia for open heart cases is encouraged where experience is available.)

5. Manage regional anesthesia cases. (Experience in the actual administration of regional anesthesia is strongly encouraged.)

6. Use and interpret a broad variety of monitoring modalities including electronic monitors--EKG, Arterial Pressures, CVP, etc.

7. Manage fluid therapy within medical plan of care.

8. Recognize and take appropriate actions with reference to complications occurring during anesthetic management, referring to a physician those beyond the nurse anesthetist's ability to manage consistent with practice standards, policies and that degree of delegation accepted from the physician.

9. Utilize mechanical ventilators effectively.

10. Position or supervise positioning of patients to assure optimal physiologic function and patient safety.

11. Function as a team leader/member in cardiopulmonary resuscitation.

12. Interpret and take appropriate actions with reference to screening pulmonary function and blood/gas determinations.

13. Serve as a resource person for respiratory care of patients.

14. Utilize appropriate principles of basic and behavioral sciences in protecting patients from iatrogenic complications.

15. Applies crisis theory in the care of patients/families and in facilitating the function of the health care team.

16. Teach patients and health related personnel in area of expertise.

17. Recognizes personal and professional strengths and limitations and takes appropriate actions consistent with valid self-awareness.

18. Knows and functions within appropriate legal requirements as a licensed professional, accepting responsibility and accountability for own practice.

D. Academic Requirements:

1. The number of contact class hours in each division shall meet or exceed the following:

a. Professional Aspects of Nurse Anesthesia: 45 hours

(1) Department management and organization.

(2) Ethics.

(3) History of anesthesia.

(4) Legal aspects of anesthesia. (Six hours)

(5) Professional Adjustments. (To include local, state, national organizational structure and current issues.)

(6) Psychology.

b. Anatomy, physiology and pathophysiology in relation to anesthesia: 135 hours

(1) Cell physiology.

(2) Nervous system.

(3) Respiratory system.

(4) Circulatory system.

(5) Endocrine system.

(6) Excretory system.

c. Chemistry and physics in relation to anesthesia: 60 hours

d. Pharmacology in relation to anesthesia: 75 hours

e. Principles of Anesthesia Practice: Basic and Advanced. 75 hours

f. Journal Club, Seminars, Morbidity and Mortality Conferences and/or other Clinical Correlative Conferences: 35 hours

NOTE: Programs/Schools should strive to exceed the 35 required hours for conferences.

2. Objectives written in behavioral terms and course outlines and reading lists shall be available for all subjects and shall be provided to students, faculty and consultants and/or other appropriate personnel.

3. Organization of curriculum and manner of implementation, while the prerogative of the faculty, must demonstrate a sequential arrangement consistent with providing an adequate theoretical base for practice in correlation with the clinical practicum and reflect the program philosophy.

E. Practicum Requirements:

The clinical teacher or supervisor is the professional person responsible for clinical instruction and the evaluation of performance concerning levels of knowledge, understanding, interpretation, application of principles, as well as the demonstration of skills.

1. An anesthesiologist or C.R.N.A. shall be immediately available in all anesthetizing areas at all times for consultation and/or assistance.

2. The ratio of students to clinical instructors shall not exceed 2:1 and shall be directly related to:

a. The student's period of enrollment in the program and his/her readiness to assume responsibility.

b. The physical status of the patient.

c. The complexity of the anesthetic and/or surgical procedure.

d. The ability of the instructor.

3. Basic Principles of Anesthesia Practice should include a broad-fields orientation to the practicum to include:

a. Preanesthesia evaluation of the patient.

(1) Interview techniques.

(2) Evaluation of the patient's chart.

(3) Physical assessment of the patient.

b. Charting.

c. Monitoring of vital signs.

(1) Elementary (palpitory, auscultatory and visual).

(2) Electronic.

d. Intravenous techniques.

e. Familiarization with basic anesthesia equipment.

f. Overview of anesthetic agents and accessory drugs.

g. Philosophy and ethics of anesthesia.

4. Student anesthesia management of the patient shall include:

a. Preoperative evaluation of patient to include interview, assessment and review of appropriate patient records (history/physical, laboratory and x-ray reports, etc.)

b. Development of a written anesthetic care plan to include selection of agents and techniques.

c. Administration of the anesthetic.

d. Decision making during the anesthesia management.

e. Immediate postanesthesia care.

f. Postanesthesia follow-up, including visits.

g. Implementation and maintenance of an accurate, complete anesthesia record.

5. Programs must demonstrate the availability of a broad variety and balance of clinical experience for student learning. This shall include experience in anesthesia for intrathoracic, intracranial, and pediatric (under two years of age) cases. The following types of clinical experience, by numbers, are required for each student:

a. Agents:

(1) Nitrous oxide .... 150 cases

(2) Intravenous barbiturates .... 100 cases

(3) Muscle relaxants .... 100 cases

(Depolarizing; non-depolarizing; including adequate recovery and/or reversal)

(4) Intravenous narcotics, neuroleptic drugs or tranquilizers .... 50 cases

(5) Inhalation agents other than nitrous oxide .... 50 cases

(Effort should be expended to provide variety in complying with this requirement)

b. Methods of anesthesia:

(1) Inhalation .... 300 cases

(a) Endotracheal (actual intubation) .. 125 cases

(b) Mask cases .... 25 cases

(2) Intravenous (actual venipuncture) ...... 100 cases

(3) Regional (management of)	15 cases
(4) Mechanical ventilation	15 cases
c. Special cases:	
(1) Emergency surgery	25 cases
(2) Geriatrics (60 years or older)	25 cases
(3) Pediatrics (12 years or younger):	
(a) Two to 12 years	10 cases
(b) Under two years	2 cases minimum; 5 cases preferred
d. Surgical anatomical categories:	
(1) Head:	
(a) Intracranial	2 cases minimum; 5 cases preferred
(b) Extracranial	10 cases
(c) Intrapharyngeal	15 cases
(2) Neck	5 cases
(3) Intrathoracic	5 cases
(4) Extrathoracic	10 cases
(5) Abdominal:	
(a) Upper	20 cases
(b) Lower	20 cases
(6) Extremities	25 cases
(7) Obstetrics (Caesarean section or Vaginal delivery)	15 cases
e. Position categories:	
(1) Procedures in the prone position	5 cases
(2) Procedures in the lithotomy position	25 cases
(3) Procedures in the lateral position	5 cases
(4) Experience with patients in sitting position encouraged.	

f. All experiences shall incorporate patient safety aspects in the learning situation to include:

(1) Correct positioning.

(2) Safety regulations as relates to electrical, explosive, thermal or other iatrogenic hazards.

(3) Testing and first echelon preventive maintenance of equipment to be used.

(4) Infection control measures as relates to patients, personnel and equipment.

g. CPR Competency: All students shall complete the Basic Life Support Course offered by the American Heart Association (or local Affiliate) or its equivalent.

h. Encouraged experiences:

(1) Anesthetic management of:

(a) Arteriogram.

(b) Pneumoencephalogram.

(c) Cardiac catheterization.

(d) Electroshock therapy.

(e) CAT Scan.

(2) Respiratory therapy (minimum of two weeks recommended).

(3) Inhalation induction.

(4) Arterial puncture (actually performed).

(5) Arterial monitoring.

(6) Central Venous Pressure (actually performed).

(7) Swan Ganz Monitoring.

(8) Open heart surgery.

i. Actual administration of Regional Anesthesia is strongly encouraged. (Statement by the Council on Nurse Anesthesia Practice on the Administration of Regional Anesthesia by Nurse Anesthetists included in the Appendices.)

6. Affiliations.

Affiliations can be a source of added richness in both depth and breadth of a program.

a. An affiliation is necessary if there is an insufficient quantity or quality of required experience to meet student needs.

b. An affiliation should be considered if there is borderline quantity or quality of required experiences to meet student needs.

c. When an affiliation is established, there shall be a written agreement between the parent and affiliate facility, outlining the expectations and responsibilities of each.

d. Terminal behavioral objectives and guidelines shall be formulated for the affiliated experience.

e. The program director, or his designee, shall periodically visit and review all affiliations to assure that program policies are being carried out and that the objectives of the affiliation are being achieved. In most instances such reviews shall be on a monthly or quarterly basis, but under no circumstances shall they be less than twice a year.

f. The quality of clinical instruction at an affiliated facility shall be comparable to that in the parent facility.

7. Anesthesia Call Experience.

a. Each student shall have anesthesia call experience, or its equivalent, as a part of the clinical practicum.

b. To assure patient safety, and student learning, the length of the call period shall not exceed 16 hours with the following day uncommitted except for scheduled classes, Monday through Friday. The number of hours of weekend call should be in relation to a realistic amount of house anesthesia time. Students shall not be assigned to practicum following call.

c. Students may acquire their anesthesia call experience while being assigned scheduled shifts (for example, 3 pm to 11 pm or 11 pm to 7 am).

d. Behavioral objectives and guidelines shall be available for anesthesia call experiences, whether scheduled as call or on a scheduled shift.

F. Teaching/Learning Methods.

A variety of teaching methods shall be used to facilitate effective learning. These may include:

1. Discussion.
2. Demonstration.
3. Lecture.
4. Laboratory.
5. Programmed instruction.
6. Audiovisual.
7. Field trips.
8. Case Study.
9. Journal club.
10. Structured self-directed learning is encouraged. This is not to exceed 15% of the required academic curriculum reflected in this standard.
11. Other.

ATTACHMENT 2

Nurse Anesthetist Training Proposal
for the
AMERICAN ASSOCIATON OF NURSE ANESTHETISTS

1. Amend Nurse Training Act, Section 831 of NTA (42 USC Section 297-1) to:

(a) Strike Section 831 (b) and substitute:

"(b) The Secretary may also make grants to public or private non-profit entities to cover the cost of projects to improve programs for the education of nurse anesthetists which are accredited by an entity or entities designated by the Secretary of Education including grants to such entities for the purpose of providing financial assistance and support to certified registered nurse anesthetists who are faculty members of accredited programs to enable them to obtain advanced education relevant to their teaching functions."

"(c) For the purpose of making grants under subsections (a) and (b), there are authorized to be appropriated $1.2 million for fiscal year 1985, $2.2 milliom for fiscal year 1986 and $3.0 million for fiscal year 1987."

Ms. Busch. I'd also like to mention that our association is generally supportive for all Nurse Training Act programs, but my testimony, of course, focuses on the anesthesia.

CRNA's, for your information, are licensed registered nurses, who have specialized in anesthesia through a 2-year postgraduate educational program and who are certified by a national certifying body. CRNA's have been administered anesthesia for close to a century. The practice is legally sanctioned in all of the States. They deliver over 50 percent of the anesthetics in this country and 70 percent in rural areas of the country. They are employees of hospitals or physician groups, they are members of the military, or they work as independent contractors.

In well over a third of the hospitals in this country, the CRNA's are the sole anesthesia providers.

The need for continued support of nurse anesthesia education can be justified in several ways. A 1977 HEW study on supply and demand of anesthesia services documents a current shortfall of between 3,000 and 6,000 nurse anesthetists. The number of nurse anesthesia programs is dropping. We are only producing about 1,200 nurse anesthetists each year, and we lose about 700 CRNA's due to retirement, death, disability each year. So our net gain is only about 500 nurse anesthetists each year.

Also, the increasing age of the American public will contribute to an increase demand for anesthesia providers in the coming years. The Census Bureau projects that the number of elderly Americans will double between the years 1980 and 2020. As the average life expectancy increases, the need for anesthesia services will increase, as older people tend to need more surgical procedures.

Finally, a major finding of a comprehensive study on nursing and nursing education referred to in the written testimony was that there is a need for expanded support of nurses practicing in clinical specialties, including nurse anesthetists.

Investments in the education of nurse anesthetists are really investments in a method of delivering high quality and very cost-effective medical care during a critical time in those patients care, when they require anesthesia for surgery.

The evidence we've submitted is that anesthesia care that's provided for CRNA's is equally good as that provided by physician anesthetists. Anesthesia by CRNA's is a means and an alternative to provide quality health care while helping to control the escalating costs of health care.

It should be noted that the median yearly income for anesthesiologists, those are the physicians specializing in anesthesia, is $150,000. The gross median income for a CRNA in 1982 was $36,700. Costs for nurse anesthesia education are escalating. This is for a number of reasons. First of all, hospitals are having difficulty in supporting educational endeavors to the extent that they have in the past.

Second, these programs are postgraduate, and they are moving into the academic settings. Hence, tuition costs are increasing. As a part of that, and because the programs must keep up with the rapid advances of the technology of this field, programs must be continually upgraded. So many programs increasing the length from 24 to 30 months.

These reasons have caused many programs to close, and today there are only 137 left in the country.

Traditionally, students often receive stipends and tuition assistance from hospitals. With increasing cost constraints put on them, that's becoming much more of a problem and that support is drying up.

As the admissions committee chairman for several years in our program in Connecticut, I've had the contact with many bright qualified nurses who inquire about the school and about nurse anesthesia. A major concern of these perspective applicants is finances for a venture which takes 2 full years and forces them to leave the job market.

These applicants must be experts in critical care nursing since the programs require them to have critical care nursing experience before they can enter. So they must return to the academic environment leaving the work setting and a salary.

It should be noted that this salary is that of a registered nurse. So saving money to support themselves for 2 years is very difficult.

I should also like to remind the committee that there are mature people who are entering the peak of their career lives. The average of our incoming class, for example, is 29½. Therefore, many of our students have families and family-related financial commitments.

As a result the lack of funding affects the student's initial career choice. After they have entered the programs their classroom and clinical commitments require over 60 hours a week.

So part-time work is not encouraged; and the programs are not structured to be completed part-time over a number of years. The curriculum must be completed because it's required for entry into practice.

The first funding for the nurse anesthetist traineeship program for fiscal year 1984 was modest, but most helpful. We are asking for expansion in the program to allow nurse anesthesia to continue to fulfill its commitment to society.

In summary, there is at present a need for about 6,000 additional CR&A's. We believe the demand and need will continue to increase.

Student financial aid is critical to help nurses complete their nurse anesthesia education programs. Our request for fiscal year 1984 for the existing Nurse Anesthesia Traineeship Program under section 831 of the Nurse Traineeship Act is $1 million which will support approximately 200 students to the level of about $5,000 a year.

For your information in the process of renewing the Nurse Training Act, additional funding is being requested for graduates who are faculty members as well. This is because the programs are moving gradually into that graduate level framework.

We need academically credentialed faculty appropriate for this. The level being requested for fiscal year 1985 is $230,000. The background information for this is cited in our written testimony.

I'd like to thank the committee for this opportunity to present this testimony. We view this proposal as an opportunity for the Federal

Government to invest in a venture which can be demonstrated to have a long-term cost-effective benefit in the provision of quality anesthesia services in this country.

The returns on such an investment cannot be ignored if health care costs are to be contained without decreasing services provided to the American people. Thank you.

Senator WEICKER. Thank you very much. You finished right on time.

Ms. BUSCH. Good.

Senator WEICKER. Thank you. We appreciate it.

Ms. BUSCH. You're welcome.

STATEMENT OF HARLEY M. DIRKS, CONSULTANT, SOCIAL POLICY NATIONAL HOMECARING COUNCIL

PREPARED STATEMENT

Senator WEICKER. Senator Burdick, you're just in time to hear our next witness, Harley Dirks, constant, Social Policy National HomeCaring Council.

Harley, nice to have you here.

Mr. DIRKS. Thank you, Mr. Chairman.

Senator WEICKER. Quen is going to take over the Chair.

Senator BURDICK [presiding]. Good morning.

[The statement follows:]

STATEMENT OF HARLEY M. DIRKS

The National HomeCaring Council, a national nonprofit standard setting, accrediting organization, promoting quality homemaker home health aide services, is pleased to present our views to your subcommittee during your consideration of appropriations for fiscal year 1985.

As you are aware, Mr. Chairman, the past several years have been highly progressive in the field of homecare. Many changes have taken place, and many new ideas have taken hold. Home care is becoming very important as a supplement to institutional treatment and care, and in many cases, a less costly alternative.

Home care is now being recognized universally as a method of providing optimal and sufficient service to individuals who are unable to perform all their daily functions, yet well enough to remain at home where they prefer to be. This, of course, is a much more human approach to assisting the disabled and elderly of the Nation.

It is clear to the National HomeCaring Council that home care alternatives, and services, will continue to grow and challenge traditional sources of care delivery.

We believe it is also very important, when assessing the coming challenges and potential growth of home care activities, that we take into consideration the changing face of the Nation's aged population. During the next 20 years, the percentage of aged individuals (those over 65), who are the most frequent users of home care services, will increase significantly. This, no doubt will challenge the Nation and the home care industry to seek even more productive and efficient means of providing home care services.

The Home Health Program administered by the Health Resources and Services Administration has made funding grants and loans to home health agencies to meet the initial costs of establishing home health agencies, to expand existing services to meet the increasing demands of the recent proliferation of care being provided, and for the training of qualified personnel to serve as homemaker home health aides, and other professionals in the field.

It appears to the National HealthCaring Council that, taking into consideration the rapid growth and change of home care services, and the industry itself—an industry that is really just stepping out of its infancy—the administration's budget proposal to totally eliminate funding for the very programs that are vital to the balanced growth and proficiency of home care, is truly a penny-wise and pound-foolish request. I can assure you there is a long way to go, to provide quality care, particularly in the area of training. Already the media is reporting several horror stories regarding untrained personnel performing functions they are not qualified to do.

The National HomeCaring Council recommends that your subcommittee provide funding for fiscal year 1985, at least at last years level of $5 million, to continue the important and sorely needed efforts of HRSA to assist in establishing and modestly expanding services, and most importantly to assist in providing professional training. This Mr. Chairman is a good investment in health care, for people who really need it.

Thank you for the opportunity to present our view.

Mr. DIRKS. Good morning, Mr. Chairman. Mr. Chairman, the National HomeCaring Council—a national nonprofit, standard-setting, accrediting organization promoting quality homemaker, home health aide services—is pleased to present our view to your subcommittee during your consideration of appropriations for fiscal year 1985.

As you are aware, Mr. Chairman, the past several years have been highly progressive in the field of home care. Many changes have taken place and many new ideas have taken hold.

Home care is becoming a very important supplement to institutional treatment and care; and, in many cases, a less costly alternative. Home care is now being recognized universally as a method of providing optimal and sufficient services to individuals who are unable to perform all their daily functions, yet well enough to remain at home where they prefer to be.

This, of course, is a much more human approach to assisting the disabled and elderly of the Nation, as well as families with children who need help to remain together when crises occur with which they cannot cope unaided.

It is clear to the National HomeCaring Council that home care alternatives and services will continue to grow as a complement to traditional sources of care delivery.

We believe it's also very important when assessing the coming challenges and potential growth of home care activities that we take into consideration the changing face of the Nation's aged population. During the next 20 years, the percentage of aged individuals—those over 65, who are the most frequent users of home care services—will increase significantly.

This, no doubt, will challenge the Nation and the home care industry to seek even more productive and efficient means of providing home care services. The Home Health Program administered by the Health Resources and Services Administration has made funding grants and loans to health agencies to meet the initial costs of establishing home health agencies to expand existing services to meet the increasing demands of the recent proliferation of care being provided, and for training of qualified personnel to serve as homemaker, home health aides and other professionals in the field.

It appears to the National HomeCaring Council that, taking into consideration the rapid growth and change of home care services, and the industry itself—an industry that it really just stepping out of its infancy—the administration's budget proposal to totally eliminate funding for the very programs that are vital to the balanced growth and proficiency of home care is truly a penny-wise and pound-foolish request.

I can assure you there's a long way to go to provide quality care, particularly in the area of training. Already, the media is reporting several horror stories regarding untrained personnel performing functions they are not qualified to do.

The National HomeCaring Council recommends that your subcommittee provide funding for fiscal year 1985 at least last year's level of $5 million to continue the important and sorely needed efforts of HRSA to assist in establishing and modestly expanding services; and, most importantly, to assist in providing professional training.

This, Mr. Chairman, is a good investment in health care for people who really need it. Thank you.

Senator BURDICK. Thank you very much. I'd like to ask you a question.

I've long been an advocate of using more home services instead of hospitalization.

Mr. DIRKS. We know you have, Mr. Chairman.

Senator BURDICK. I think I've been influential in having the University of North Dakota go into this in depth; and the subject matter you talked about this morning covers that area, too, doesn't it?

Mr. DIRKS. Yes, sir.

Senator BURDICK. Thank you for your testimony.

Mr. DIRKS. Thank you, Mr. Chairman.

STATEMENT OF HARMON E. HOLVERSON, M.D., PRESIDENT, AMERICAN ACADEMY OF FAMILY PHYSICIANS

ACCOMPANIED BY ARDEN ANDERSON, M.D., CHAIRMAN OF THE BOARD

PREPARED STATEMENT

Senator BURDICK. The next witness is Harmon Holverson, M.D., president, the American Academy of Family Physicians.

Welcome to the committee, Dr. Holverson.

Dr. HOLVERSON. Thank you, Senator Burdick.

I have brought a sidekick along with me, Dr. Arden Anderson, who is also a practicing family physician and is currently serving as chairman of the board of the American Academy of Family Physicians.

[The statement follows:]

STATEMENT OF HARMON E. HOLVERSON, M.D.

Mr. Chairman and members of the subcommittee, I am Harmon E. Holverson, M.D., a practicing family physician from Emmett, Idaho currently serving as President of the American Academy of Family Physicians. Our Academy represents 57,000 family physicians and medical students in each of the 50 states as well as the District of Columbia, Puerto Rico and the Virgin Islands. We appreciate the opportunity to appear before you as we have in the past to ask for your help in maintaining federal funding of family practice training programs.

The two sections which are of key concern to our Academy are Sections 780 and 786. Section 780 authorizes grants to schools of medicine to establish, maintain and/or improve academic and administrative units to provide clinical instruction in family medicine. Currently 74% of U.S. medical schools (103 out of 138) have departments of family practice. The maintenance of this academic base for family practice within medical schools is crucial to the specialty's ability to remain viable in an environment of scarce economic resources. The current appropriation for this section is $7.790 million. The second section of particular concern is Section 786 which provides grants to support residency training programs in family practice, faculty development and pre-doctoral training in family medicine. The funds authorized by Section 786 have been used to establish new and maintain and improve existing family medicine residency programs. These residency programs teach comprehensive preventive care in an ambulatory setting. Currently the appropriation for Section 786 is $34 million.

This Academy is deeply appreciative of the support that Congress has given to family practice training. I would like to review with you some of the positive results of this investment and explain to you why continued federal support is necessary if the progress in the past decade of addressing problems of specialty and geographic maldistribution is to be maintained. With the assistance of generous federal support, family practice in the

United States has experienced tremendous growth--from 15 approved residency programs in 1969 to 387 at the present time. As shown in Attachment A, the number of residents now in family practice residency programs is 7,409. This dramatic increase in the number of residency programs has made a significant contribution to correction of the problems of specialty and geographic maldistribution. Survey data that the AAFP has collected since 1975 shows that graduates of family practice residency programs are locating their practices in rural as well as urban areas. As you will note in Attachment B, approximately 50% of these family physicians enter practice in communities with populations of 25,000 or less and over half of these are locating in areas not within 25 miles of a large city. With respect to retention in the specialty of family practice, survey responses from 1,591 individuals who completed family practice residency training in July 1983 indicate that less than 4 percent intend to pursue other specialty or subspecialty training. Our residency graduates are staying in the specialty of family practice. We believe that these figures demonstrate that increased patient access to medical care has been a direct result of the growth of family practice in this country. We hope you agree that this federal financial investment has had a positive effect on the nation's health care delivery system.

However, we are concerned that proposed cuts in these family practice programs will erode the progress that has been made to date. Federal funding is uniquely vital to the operation of family practice residency programs because the programs themselves are unique. The skills and procedures which are taught to family practice residents and which emphasize ambulatory care and disease prevention, contribute to better health and more cost effective health care, but do not generate patient revenues sufficient to underwrite graduate training in family medicine. Third party reimbursement falls short as a financial foundation for family practice training because such coverage has a bias toward inpatient care. These residency programs do not fit the traditional graduate medical education mold and as such can not live up to the expectation that family practice education in common with other graduate medical education ultimately must be supported largely from patient care income. This conclusion has been documented in a 1981 study done by the University of Missouri at Columbua. This study documents what family medicine educators have been facing. Uncontrollable factors keep costs high and income from patient care low. While traditional theory holds that approximately one half of program costs should be recoverable through income from patient care, reality shows that to be unrealistic for family practice, where the average family practice residency generates only 20% of total program costs through patient revenues.

The AAFP and family medicine educators continue to seek viable alternative sources for meeting program costs; but for now, federal support is crucial. To quote the University of Missouri study: "The future of family medicine education is highly dependent upon a widespread understanding that its financing needs are different. Family medicine has been supported as a national priority with high standards for training and certification, a potential for overcoming maldistribution problems, and an emphasis upon ambulatory rather than expensive inpatient care. In a sense, these are societal as well as program goals and a continued sharing of the costs of training is essential."

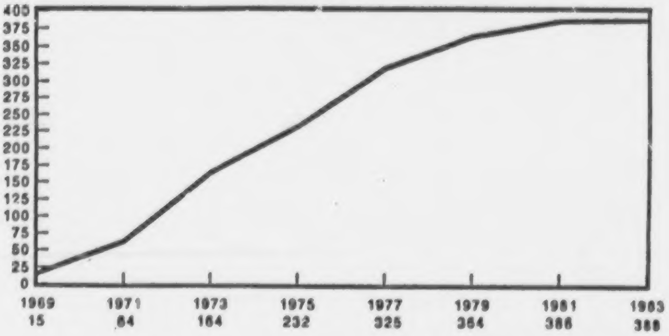
The AAFP in conjunction with the American Society of Internal Medicine has been working with the Senate Finance Committee and the Health Subcommittee of the House Committee on Energy and Commerce to have language included in the reconcilation package which would require a study of ways to modify the existing physician reimbursement system under Medicare in order to eliminate inequities that exist between reimbursement levels for procedural versus cognitive services. Additionally, the House language makes particular mention of inequities in relative amounts paid to physicians by type of service, locality and specialty. The AAFP is hopeful that, should these provisions be enacted, the resulting study will provide Congress with potential legislative solutions to the current payment inequities. Such changes in the Medicare payment system will be beneficial in assisting family practice residency programs to generate a higher percentage of the necessary revenues from patient care income, although it is not known at this time if these unique residency programs can ever compete financially with inpatient-based residency programs and reach a point where targeted federal assistance is no longer necessary.

The American Academy of Family Physicians is well aware of and sympathetic to the economic constraints which will influence the decisions in this committee in making appropriations of federal funds. We believe, however, that these critical times make it all the more imperative that federal funds are expended in such a way as to do the most good for the greatest number of people. With respect to funding for family practice education, the AAFP sincerely believes that the funds expended to date have resulted in improved access to high quality, comprehensive medical care. We therefore request that the Fiscal Year 1985 appropriation for Section 780 remain at the current level of $7.790 million and that the FY 85 appropriation for Section 786 be slightly increased from the current appropriation level of $34 million. We believe that these requests are consistent with the Congressional effort to restrain spending for discretionary health programs, yet are cognizant of the need for continued federal support of family practice training. We believe that this federal investment in family practice has and will continue to have beneficial results for society.

Thank you for your consideration. I will be happy to answer any questions that you have at this time.

Attachment A

ACCREDITED FAMILY PRACTICE RESIDENCIES
JULY 1983



The American Academy of Family Physicians AAFP 150-B

ATTACHMENT B

AAFP Reprint No. 1581

American Academy of Family Physicians

REPORT ON SURVEY OF 1983 GRADUATING FAMILY PRACTICE RESIDENTS

The total number of graduates surveyed was 2117. Of this number 1632 (77%) responded. Of these respondents, 1591 indicated the type of practice arrangement and 1363 specified the size of the community in which they plan to serve. A summary of the results as of July 1983 follows.

The data from 1977, 1978, and 1979 has been re-analyzed to conform with the 1980-1983 statistics. Caution must be exercised in comparing data previous to 1977 because of changes made to data analysis. However, the revised 1977-1979 data may be directly compared with the 1980-1983 data with confidence.

PRACTICE ARRANGEMENTS OF 1983 GRADUATING RESIDENTS

Type of Practice Arrangements	Number of Reporting Grads	Percentage of Total Reporting Grads
Family Practice Group	336	21.1%
Multi-Specialty Group	154	9.7%
Two-Person Family Practice Group (Partnership)	245	15.4%
Solo	254	15.9%
Practice (arrangement not specified)	43	2.7%
Military	121	7.6%
Teaching	62	3.9%
USPHS	133	8.3%
Emergency Room	97	6.1%
Hospital Staff	25	1.6%
Research	4	.3%
Administrative	1	.1%
Further Training	30	1.9%
Fellowship	30	1.9%
None of the above	56	3.5%
	1,591	100.0%

DISTRIBUTION OF 1983 GRADUATING RESIDENTS BY COMMUNITY SIZE

Character and Population of Community	Number of Reporting Grads	Percentage of Total Reporting Grads	Cummulative Percentage of Total Reporting Grads
Rural area or town (less than 2500) not within 25 miles of large city	112	8.2%	8.2%
Rural area or town (less than 2500) within 25 Miles of large city	26	1.9%	10.1%
Small town (2500-25,000) not within 25 miles of large city	342	25.1%	35.2%
Small town (2500-25,000) within 25 miles of large city	191	14.0%	49.2%
Small city (25,000-100,000)	246	18.1%	67.3%
Suburb of small metropolitan area	40	2.9%	70.2%
Small metropolitan area (100,000-800,000)	122	9.0%	79.2%
Suburb of large metropolitan area	146	10.7%	89.9%
Large metropolitan area (800,000 or more)	81	5.9%	95.8%
Inner city/low income area (800,000 or more)	57	4.2%	100.0%
	1,363	100.0%	

Dr. HOLVERSON. As you see by our written testimony, I am serving as the president of the academy. We represent over 57,000 physicians and medical students throughout the States, the 50 States, as well as the District of Columbia, Puerto Rico, and the Virgin Islands; and we really appreciate the opportunity to appear before you as we have in the past to ask for your help in maintaining Federal funding for family practice during the coming years.

Senator Burdick, we particularly appreciate the support that you have given the family practice in the past.

The two sections that are of particular concern to the academy at the present time are sections 780 and 786; 780, as you know, authorizes the grants to schools to establish, maintain and improve academic administrative units to provide clinical instruction. There are currently about 74 percent of the medical schools in the United States that have these departments, or 103 out of 138.

The second section that is of particular concern to us is section 786 which provides grants to support residency training programs in family practice. This also supports faculty development and predoctoral training in family medicine, also.

The funds that have been used in section 786 are used to maintain and to improve existing family medicine programs. These programs are different than the usual residency program in that they teach comprehensive, preventive care in an ambulatory setting.

The academy is deeply appreciative of the support that Congress has given the family practice training in the past and we have had some positive results as a result of this type of training. I'd like to emphasize those at this time and sort of explain why we feel that continued Federal support is necessary.

With the assistance that we've had in the past, our programs have demonstrated a dramatic growth from 15 approved residency programs in 1969 to 387 at this time, and we now have 7,409 residents in training. What this has done, we feel, is to improve dramatically the geographic maldistribution that has existed and has improved the availability of family physicians to many of the people in our country.

We have a survey—and the attachment is noted on our written testimony—which indicates that around 50 percent of these family physicians that are trained are practicing in areas or communities with populations of 25,000 or less and over half of these are in areas that are not within 25 miles of large cities. I might point out that two of the graduates of the North Dakota program have come to my small town of Emmet, ID, as a matter of fact, which has only 4,800 people.

Now, it's interesting that one of the things that has come up about this is whether or not we retain these graduates. In a recent survey that we did, we show that only 4 percent of the graduates of these family practice programs go into other areas.

So we feel that our residency graduates are staying within the specialty of family practice.

We're concerned, however, that if the proposed cuts that are potential occur they will erode the progress that's been made; and that if this program is cut, that we will not be able to continue to produce and to increase the numbers of family physicians and give the balance of care that we feel we're getting at the present time.

The family practice residencies are unique in that they do not have the financial ability that other inpatient residency programs have because our programs exist in an ambulatory center and they treat ambulatory patients and provide preventive care, and third-party reimbursement doesn't really help us. So we need Federal funding to help support these programs.

A study that was done in 1981 by the University of Missouri at Columbia really demonstrated that only about 20 percent of the funding necessary for the programs can be generated by the program from patient revenues. They stated, and I quote:

> The future of family medicine education is highly dependent on a widespread understanding that its financing needs are different.
>
> Family medicine has been supported as a national priority with high standards for training and certification, a potential for overcoming maldistribution problems, and an emphasis on ambulatory rather than expensive inpatient care.

Now, because of this, we're requesting that section 780 remain at the current level of $7.79 million and section 786 should be slightly increased so that we may need the incoming students and produce a level of response that will maintain family practice where it is today.

Thank you very much for your consideration and I'll be happy to answer any questions that you might have at this time.

Senator BURDICK. Do you believe that the family practitioners are more likely to stay in the rural areas of North Dakota and Idaho if they have this type of expertise?

Dr. HOLVERSON. Yes; I definitely believe that. I think our programs have shown that.

Senator BURDICK. You have so many people, particularly the foreign country doctors that come into my State, that use it as a stepping stone to go on elsewhere; and generally these people who take family practice, I think, are motivated to stay in their own States. That's the feeling I get from what I've seen.

Dr. HOLVERSON. I think we've shown this in the past.

Senator BURDICK. We don't have these people who fly off to the big cities and the big fees, and everything. They feel content to serve their fellow men in their own back yard, so to speak.

Dr. ANDERSON. I fully agree, Senator Burdick. I'm a native North Dakotan, and a graduate.

Senator BURDICK. I thought there was something nice about you. [Laughter.]

Dr. ANDERSON. Well, we've met before; and I couldn't agree more. As you and I both know, the efforts in the State of North Dakota have been very fruitful as far as providing people in that State with family doctors who can care for people in small communities.

Senator BURDICK. The main thing is to have them stay there and not run off to the bright lights.

Dr. HOLVERSON. I practice in a small town, too. I practice in the town that I was born in,——

Senator BURDICK. Well.

Dr. HOLVERSON [continuing]. Which is an unusual situation, but there are a lot of us that go back to the small areas we've come from.

Senator BURDICK. Well, thank you for your testimony. I think you've presented a pretty good case.

Dr. HOLVERSON. Thank you very much, Senator.

Dr. ANDERSON. I'd like to echo our appreciation for all your help in the past.

Senator BURDICK. Thank you.

The next witness will be William Neal, president of the National Perinatal Association. Is he here, Mr. Neal?

[No response.]

STATEMENT OF DR. MARCELLUS GRACE, DEAN, XAVIER UNIVERSITY SCHOOL OF PHARMACY

ACCOMPANIED BY:

DR. HENRY LEWIS, ASSISTANT DEAN, COLLEGE OF PHARMACY AT FLORIDA A&M

DR. AL ABADE, ASSOCIATE DEAN, TUSKEGEE INSTITUTE VETERINARY MEDICINE PROGRAM

PREPARED STATEMENT

Senator BURDICK. Well, the next one is Dr. Marcellus Grace, the Xavier University School of Pharmacy.

Dr. GRACE. I'd like to introduce several of my colleagues. I'm Dr. Marcellus Grace, a pharmacist and dean of the Xavier University College of Pharmacy. I have with me present this morning Dr. Henry Lewis, the assistant dean of the College of Pharmacy at Florida A&M at Tallahassee, and Dr. Al Abade, the associate dean of the Tuskegee Institute Veterinary Medicine Program.

[The statement follows:]

STATEMENT OF DR. MARCELLUS GRACE

Thank you for the opportunity to present the views of the Association of Minority Health Professions Schools regarding Appropriations for Fiscal Year 1985 for programs necessary to the education of minorities in the health professions. I will present a brief statement and submit our Appropriations recommendations for your review and the hearing record.

The member institutions of the Association, the Morehouse School of Medicine, Tuskegee Institute School of Veterinary Medicine, Xavier University of Louisiana, Florida A&M University College of Pharmacy, Texas Southern University School of Pharmacy, Charles R. Drew Postgraduate Medical School, and the MeHarry Medical and Dental Colleges, all maintain a vital interest in the programs in the Department of Health and Human Services, and the Department of Education, that are funded by your Subcommittee. The eight institutions represented by our Association have graduated 43 percent of the nation's black physicians and dentists, 50 percent of the nation's black pharmacists, and 90 percent of the nation's black veterinarians. Many programs contained under your Appropriation jurisdiction profoundly effect the educational missions and success of our institutions, and our collective and individual goals to increase the number of black and other minority health professionals in the nation. The institutions represented by the Association, as well as our students, rely heavily upon this Federal support.

President's Budget Proposals for Health Professions

The President's Budget proposal for fiscal year 1985 requests Congress to eliminate and/or make significant cuts in health professions and educational aid programs that are vital to the survival and maintenance of the progress being made by minority institutions and minority students. In fact, the President's budget for health professions for FY 1985 proposes cuts of $85 million from the current FY 1984 program levels, and countless millions in funds for student assistance for the

Department of Education programs that provide basic aid to thousands of undergraduate and postgraduate students in the nation. Of these cuts, several reach deep into the financial base that is necessary for many minority students to begin and continue their education. Funds for Health Professions Student Loans, Exceptional Financial Need, Financial Distress, and National Health Service Corps Scholarships that many former EFN recipients receive to continue their medical education have been proposed for elimination, or significant reduction. While Guaranteed Student Loans and Pell Grants have been proposed to be funded at current levels, the National Direct Student Loan Program has been proposed reduced by over $150 million. Further, the Administration, while proposing elimination or reduction of many of these programs, points to other existing sources of available funding that carry high, prohibitive interest rates, that in many cases force low-income minorities and others into high paying medical specialties, thus subverting the goals of many of our minority institutions to train professionals to serve in primary care, in underserved areas. The Association of Minority Health Professions Schools does not believe this budget adequately reflects, by any means, the Administration's current alleged commitment to accelerate efforts to strengthen minorities in the health professions.

It is clear to the member institutions of our Association that we will once again have to count on Congress to express a real interest and provide funding for many of these vital programs, despite the Administration's proposals.

Comprehensive Study Finds Severe Shortages of Minorities in the Health Professions

On June 16, 1983, at a press conference in the U.S. Capitol, a comprehensive study, funded by the Robert Wood Johnson Foundation, was announced--"Blacks and the Health Professions in the 80's: A National Crisis and a Time for Action." This study documents the severe shortage of black physicians, dentists, veterinarians and pharmacists in the United States. I am pleased to submit copies of this study to the Committee, which contains abundant data to support the conclusions I cite today.

Although blacks represent 11.7 percent of the U.S. population, only 2.6 percent of the Nation's physicians are black; 2.9 percent of the dentists; 2.3 percent of the pharmacists; and 1.6 percent of the veterinarians. While there may be an emerging overall surplus of health manpower in the Nation, there continues to be an acute shortage of black health professionals. This study also illustrates, in many ways, how the inequity of minorities in the health professions reflects upon other areas of minority livelihood, such as health and economic status and stability. Clearly, with the results of this startling study, we feel it is important that many programs for health professions, funded by your Subcommittee be strengthened, and top priority given to institutions that train minorities in the health professions, and to students who attend these institutions.

Mr. Chairman, The Association of Minority Health Professions Schools, as well as the students who attend our institutions, implore your subcommittee to fund programs vital to the equity of minority participation in the health professions at levels that provide for the eventual degree of institutional and student self sufficiency that is highly desired by the members of our Association. We also look forward to working with your subcommittee in the near future to implement and fund legislative initiatives that have been set forth by our Association to begin a comprehensive National effort that will assist minorities in realizing their long term educational and professional goals.

Thank you for the opportunity to present our views. I would be happy to respond to any questions you have.

APPROPRIATIONS RECOMMENDATIONS FOR FISCAL YEAR 1985
ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Department of Health & Human Services

A. Financial Distress Grants:

'84 Actual $	'85 President's $	'85 AMHPS $
5.6 million	4.2 million	5.6 million

The Association of Minority Health Professions Schools recommends an FY '85 Appropriation of $5.6 million, consistent with the FY '84 Appropriation. This recommendation is $1.4 million higher than the recommendation of the Advanced Financial Distress Grant Panel appointed by the Secretary of Health and Human Services. Financial Distress Grants are vital to MeHarry Medical and Dental Schools, Tuskegee Veterinary School, and Xavier Pharmacy School.

B. Disadvantaged Assistance:

'84 Actual $	'85 President's $	'85 AMHPS $
18.2 million	24 million	24 million

The Association of Minority Health Professions Schools recommends an FY '85 appropriation of $24 million, consistent with the Administration's budget request. Disadvantaged Assistance Grants and Contracts are vital to the identification, recruitment, retention and placement of minority and disadvantaged students.

C. Student Assistance for Disadvantaged:

'84 Actual $	'85 President's $	'85 AMHPS $
0	5 million	5 million

The Association of Minority Health Professions Schools recommends an FY '85 Appropriation of $5 million, consistent with the Administration's budget request. Student Assistance for Disadvantaged funds will assist in addressing the problem of under representation of minorities in the health professions.

D. Exceptional Financial Need:

'84 Actual $	'85 President's $	'85 AMHPS $
5.6 million	0	5.6 million

The Association of Minority Health Professions Schools recommends an FY '85 appropriation of $5.6 million, the same as last year's appropriation. These funds are allocated to health professional schools that award students with exceptional need, scholarships for their first year of post-baccalaureate study.

E. National Health Service Corps Scholarships:

'84 Actual $	'85 President's $	'85 AMHPS $
6.3 million	0	6.3 million

The Association of Minority Health Professions Schools recommends an FY '85 appropriation of $6.3 million to assure a continuous flow of minority and other physicians to underserved areas that are, in many cases, populated by minorities. This is consistent with last year's appropriation. In addition, a large portion of new NHSC scholarships are awarded to former Exceptional Financial Need Scholarship recipients.

F. Health Professions Student Loans:

'84 Actual $	'85 President's $	'85 AMHPS $
0	0	5 million

The Association of Minority Health Professions Schools recommends an FY '85 Appropriation of $5 million for Health Professions Student Loans. The amount should be used to boost and bolster revolving funds aailable at minority health professions institutions. Many minority institutions have not had sufficient resources to develop and maintain these funds.

G. Health Education Assistance Loans:

'84 Actual $	'85 President's $	'85 AMHPS $
225 million-no limit	175 million	225 million-no limit

The Association of Minority Health Professions Schools recommends that there be at least $225 million available, or no limit placed upon these loans. Even these high interest loans are necessary, in light of other severe budget restrictions.

Department of Education

A. Guaranteed Student Loans:

'85 Actual $	'85 President's $	'85 AMHPS $
2.3 billion	2.8 billion	2.8 billion

The Association of Minority Health Professions Schools recommends an FY '85 Appropriation of $2.8 billion, consistent with the Administration's request, and that all students be required to establish remaining need to qualify for loans. The Association also recommends that a special portion of GSL funds be set aside to provide additional and separate Guaranteed Student Loans to health professions students who demonstrate financial need for their remaining years of training.

B. Pell Grants:

'84 Actual $	'85 President's $	'85 AMHPS $
2.8 billion	2.8 billion	2.8 billion

The Association of Minority Health Professions Schools recommends an Appropriation of $2.8 billion for Pell Grants. These grants provide financial assistance to help financially needy undergraduate students meet education costs.

C. National Direct Student Loans:

'84 Actual $	'85 President's $	'85 AMHPS $
161 million	0	161 million

The Association of Minority Health Professions Schools recommends an FY '85 Appropriation of $161 million for direct student loans to enable needy student to finance the costs of post-secondary education.

Dr. Grace. I would like to thank you for allowing us to come to present our views on minority health education. We have submitted copies of our study that I mentioned this morning, and we have some attached budget recommendations.

The member institutions of the association—the More House School of Medicine, Tuskegee Institute School of Veterinary Medicine, Xavier University of Louisiana College of Pharmacy, Florida A&M College of Pharmacy, Texas Southern University School of Pharmacy, Charles R. Drew Postgraduate Medical School, and the MeHarry Medical and Dental Colleges—all maintain a vital interest in the program in the Department of Health and Human Services and the Department of Education that are funded by your subcommittee.

The eight institutions represented by our association have graduated 43 percent of the Nation's black physicians and dentists, 50 percent of the Nation's black pharmacists, and 90 percent of the Nation's black veterinarians. Many programs contained under your appropriation jurisdiction profoundly affect the educational missions and success of our institutions and our collective and individual goals to increase the number of blacks and other minority health professionals in the Nation.

The institutions represented by the association as well as our students rely heavily upon this Federal support. The President's budget proposal for fiscal year 1985 requests Congress to eliminate and/or make significant cuts in the health professions and educational aid programs that are vital to the survival and maintenance of the progress being made by minority institutions and minority students.

In fact, the President's budget for health professions for the fiscal year 1985 proposed cuts of $85 million from the current fiscal year 1984 program levels and countless millions in funds for student assistance for the Department of Education programs that provide basic aid to the thousands of undergraduate and postgraduate students in the Nation.

Of these cuts, several reach deep into the financial base that it necessary for many minority students to begin and continue their education. Funds for health profession student loans, exceptional financial need, financial distress, and National Health Service Corps scholarships that many former EFN recipients receive to continue their medical education have been proposed for elimination or significant reduction.

While guarantee student loans and Pell grants have been proposed to be funded at current levels, the National Direct Student Loan Program has been proposed to be reduced by over $150 million.

Further, the administration, while proposing the elimination or reduction of many of these programs, points to other existing sources of available funding that carry high prohibitive interest rates that, in many cases, force low-income minorities and others into high paying medical specialties thus subverting the goals of many of our minority institutions to train professionals to serve in primary care in underserved areas.

I might add a comment to the previous speakers'. We have some of the same concerns about minorities staying in the minority and low and underserved, perhaps even rural areas.

The Association Minority Health Professional Schools does not believe this budget adequately reflects, by any means, the administration's current alleged commitment to accelerate efforts to strengthen minorities in the health professions. It is clear to the member institutions of our association that we will once again have to count on Congress to express a real interest and provide funding for many of these vital programs despite the administration's proposals.

On June 16, 1983, at a press conference in the U.S. Capitol a comprehensive study funded by the Robert Wood Johnson Foundation was announced, "Blacks in the Health Professions in the 1980's: A National Crisis and a Time for Action."

This study documents the severe shortage of black physicians, dentists, and veterinarians and pharmacists in the United States. I am please to submit a copy of this to the committee which contains abundant data to support the conclusions I cite today.

I will give you a personal copy. We had submitted copies previously.

Senator BURDICK. We will receive this for the file.

Dr. GRACE. Although blacks represent 11.7 percent of the U.S. population, only 2.6 percent of the Nation's physicians are black, 2.9 percent of the dentists, 2.3 percent of the pharmacists, and 1.6 percent of the veterinarians.

Where there may be an emerging overall surplus of health manpower in the Nation, there continues to be an acute shortage of black health professionals.

This study also illustrates in many ways how the inequity of minorities in the health professions reflect upon other areas of minority livelihood, such as health and economic status and stability.

Clearly, with the results of this startling study, we feel it is important that many programs for health professions funded by your subcommittee be strengthened and top priority given to institutions that train minorities in the health professions and to students who attend these institutions.

Mr. Chairman, the Association of Minority Health Professional Schools as well as the students who attend these institutions implore your subcommittee to fund programs vital to the equity of minority participation in the health professions at levels that provide for the eventual degree of institutional and student self-sufficiency. That is highly desired by the members of our association.

We also look forward to working with your subcommittee, and that has been set forth by our association to implement and fund legislative initiatives, and a copy is attached of our formal testimony, and implore you to assist us in realizing our long-term educational and professional goals.

Thank you for the opportunity to hear our comments, and I would be happy to respond to any specific questions.

Senator BURDICK. Well, I am very much apprised of the problems you have in these areas. I presume that most of your prospective clients come from the cities.

Do you have many who are from rural areas?

Dr. Black. Yes; we do. For example, my colleague here from Tuskegee Institute. I am a native Alabamian from a very small town. At my school of pharmacy in New Orleans we are continuing to draw—a lot of our students come from west Louisiana, Lafayette, Apaloosa, and small towns like that. New Orleans is, yes, the highest density area, and a lot of our graduates do go back, especially in the Southeast, small towns in Alabama, Mississippi, Georgia—primarily in Mississippi and parts of southwest Louisiana, which is probably one of our most sparsely populated areas.

Senator Burdick. What kind of service is available to the big cities—Philadelphia, Chicago, and the rest?

Dr. Black. Well, you will find in a lot of the large cities, especially in the low-income areas, it is very difficult to get practitioners to locate in those areas.

As you know, there have been some of the position shortage areas that actually have been designated in large metropolitan areas. It is especially majority positions and other health professions tend to locate in the suburban shopping—well, more lucrative income areas, and so you will find even in the pharmacies it is difficult because of the high crime and the robberies, and all that.

Even in Washington you will notice that a lot of the stores up and down Georgia Avenue are predominantly black-operated pharmacies. People's Drug Stores is not too interested, for example, here in Washington in locating some stores in these high risk areas.

Senator Burdick. And you think this legislation would help in those areas?

Dr. Black. Yes; I think so. Studies have shown that, in fact, minority health practitioners do tend to relocate back in the predominantly black neighborhoods, often back in the neighborhoods where they even grew up, much like you see in rural North Dakota, the same sort of phenomenon.

Senator Burdick. Thank you very much.

Dr. Black. Thank you very much.

STATEMENT OF WILLIAM A. NEAL, PRESIDENT, NATIONAL PERINATAL ASSOCIATION

PREPARED STATEMENT

Senator Burdick. Mr. Neal, I understand you have just arrived. We were just ready to close the shop. [Laughter.]

Dr. Neal. I am sorry to be late, Senator. I just stopped to see my home State Senator, Senator Randolph, and he talked a little longer than——

Senator Burdick. As long as you were talking to Jennings, I will forgive you. [Laughter.]

As has been stated earlier, your prepared statement will be inserted in the record at this point.

[The statement follows:]

STATEMENT OF WILLIAM A. NEAL

My name is William A. Neal, M.D. and I am a neonatologist, a pediatrician who cares for critically ill babies. I represent the National Perinatal Association, an organization comprised of 5,000 members of all health care disciplines including obstetricians, pediatricians, neonatologists, nurses, dieticians, social workers, therapists and parents who care for mothers and babies. The National Perinatal Association believes that health is influenced by all factors in the human life cycle which affect the well-being of the family prior to conception through the next generation. The Association and its members are dedicated to promoting perinatal health through fostering delivery of optimal care, education, research and ordering of national priorities. The national priority about which we are concerned right now is the amount of money we spend in this country on pregnant women and children. We recommend $499 million for the Maternal and Child Health Block Grant. The President has requested in his budget that $407 million be allocated to the Maternal and Child Health Block Grant for programs across the country. This is an amount that reflects only a 2% increase over the amount spent in 1984. In light of inflation and the tremendous expense to our Federal budget for sickness care under Medicare and Medicaid, we need to decide, and the National Perinatal Association recommends, that we shift our priorities to preventive services to mothers and children. Unless we increase the MCH Block Grant, we will continue to inadequately address perinatal care at a time when we still rank 16th as a nation among other developed countries in infant mortality. Infant mortality being only one maternal and child health area in which we could and should show improvement as a result of perinatal care. If you put aside the moral, ethical and societal reasons why women and children should have increased funding for health services, you can just look at the cold, hard money facts. That is, paying for prenatal care and maternal and child health services is cost effective. Paying for sustainment and growth of maternal and child health programs is an investment in the future and it will save in Medicaid expenses many time over. For example, paying for adequate preventive prenatal care programs means saving extraordinary amounts of money in high-risk, crisis-oriented health care, which drains our country's financial system for the life of an affected child. Daily I deal with the results of inadequate prenatal care in the sick infants whom I treat. It hurts to think that many of these babies need not be under intensive care.

I know that your humanitarian and economic instincts would guide you to support $499 million for the MCH Block Grant because:

- There is a direct relationship to the reduction of infant mortality and morbidity through prenatal care;
- It is good health policy to provide prenatal care which is basically preventive in nature, because it helps to assure healthy babies;
- It is cost effective -- good prenatal care costs hundreds of dollars yet care for one retarded child institutionalized for life will cost close to one-half million dollars. Even if the child is not retarded, intensive newborn care is averaging $30,000 per child, an expense we can prevent in many cases through prenatal care;
- And for the infant who needs intensive care, thank goodness we do have the knowledge and skill to help that baby.

Mothers and babies are traditionally silent in the halls of Congress. We do not see them lobbying or forming PACs. Children cannot vote or communicate directly with legislators. They cannot work to influence political parties or make campaign contributions. This vulnerable population is completely dependent on people like you to represent their best interests. My wish is that you do that by increasing the maternal and child health funding to $499 million.

Dr. NEAL. My name is Dr. William Neal, and I am a neonatologist at West Virginia University and a pediatrician who cares for critically ill babies. I represent the National Perinatal Association, which is an organization comprised of 5,000 members of health care disciplines, including obstetricians, pediatricians, neonatologists, nurses, dieticians, social workers, therapists, and the consumer, parents who care for their mothers and babies.

The National Perinatal Association believes that health is influenced by all factors in the human life cycle which affect the well-being of the family prior to conception through the next generation.

The association and its members are dedicated to promoting perinatal health through fostering delivery of optimal care, education, research, and ordering of national priorities.

The national priority about which we are concerned at the present time is the amount of money we spend in this country on pregnant women and children. We recommend $499 million for the maternal and child health block grant.

The President has requested in his budget that $407 million be allocated to the maternal and child health block grant for programs across the country. This is an amount that reflects only a 2-percent increase over the amount spent in 1984.

In light of inflation and the tremendous expenses to our Federal budget for sickness care under medicare and medicaid, we need to decide, and the National Perinatal Association recommends, that we shift our priorities to preventive services to mothers and children.

Unless we increase the MCH block grant, we will continue to inadequately address perinatal care at a time when we still rank 16th as a Nation among other developed countries in infant mortality, infant mortality being only one maternal and child health area in which we could and should show improvement as a result of improved perinatal care.

If one puts aside the moral, ethical, and societal reasons why women and children should have increased funding for health services, you can look at this issue from a fiscal point of view; that is, paying for prenatal care and maternal and child health services is cost effective. Paying for sustainment and growth of maternal and child health programs is an investment in the future, and it will save in medicaid expenses many times over.

For example, paying for adequate preventive prenatal care programs means saving extraordinary amounts of money in high-risk, crisis-oriented health care, which drains our country's financial system for the life of an affected child.

Daily, I deal with the results of inadequate prenatal care in the sick infants whom I treat. It is disturbing to think that many of these babies need not be under intensive care.

I am confident that your humanitarian and economic instincts justify your support of $499 million to the MCH block grant because:

There is a direct relationship to the reduction of infant mortality and morbidity through prenatal care.

It is good health policy to provide prenatal care which is basically preventive in nature, because it helps to ensure healthy babies.

It is cost effective. Good prenatal care costs hundreds of dollars, yet care for one retarded child institutionalized for life will cost approximately $500,000. Even if the child is not retarded, intensive newborn care is averaging $30,000 per child, an expense we can prevent in many cases through good prenatal care.

And for the infant who needs intensive care, we are thankful that we do have the knowledge and skill to help that given baby.

Mothers and babies are traditionally silent in the halls of Congress. We do not see them lobbying or as parts of political action groups. Children cannot vote or communicate directly with legislators. They cannot work to influence political parties or make campaign contributions. This vulnerable population is completely dependent on people like you to represent their best interests.

My wish is that you do this by increasing maternal and child health funding to $499 million.

Thank you, Senator.

Senator BURDICK. Thank you very much.

Dr. NEAL. Yes, sir.

STATEMENT OF JARRETT M. WISE, RPA-C, PAST PRESIDENT, AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

PREPARED STATEMENT

Senator BURDICK. Jarrett Wise, past president, American Academy of Physician Assistants.

[The statement follows:]

STATEMENT OF JARRETT M. WISE

Mr. Chairman and members of the committee, I am Jarrett M. Wise, former president of the American Academy of Physician Assistants. The Academy is the national professional society for physician assistants and I am pleased to have this opportunity to present our recommendations regarding FY 85 appropriations for physician assistant educational program assistance.

At present there is no official authorization for physician assistant programs. It is our understanding that the Senate Labor and Human Resources Committee chairman Orrin Hatch will introduce legislation that includes PA program reauthorization at $5 million for FY 85, 86 and 87. The House Energy and Commerce Health Subcommittee, chaired by Representative Henry Waxman, has not as yet determined what funding levels it will recommend for PA program reauthorization.

However, we are confident that the Senate and the House will recognize the need for reauthorization of funding support for PA program educational assistance. We strongly urge that the Senate Labor-Health and Human Services-Education Appropriations Subcommittee recommend continued appropriation of funds for physician assistant programs at the level being considered by the Senate Labor and Human Resources Committee. For FY 85, a minimum appropriation of $5 million is needed for physician assistant programs to continue to recruit, educate and deploy physician assistant graduates.

COST EFFECTIVENESS

For over a decade, Congress and past Administrations -- Republication and Democratic alike -- have supported the development of the PA profession because of the potential for reducing health care costs and for providing health care in underserved areas. The potential for cost savings in the provision of health care by utilization of physician assistants has never been more important than it is today. As health care expenditures continue to rise on a national level, physician assistants offer the most significant means of reducing costs while maintaining the level of the quality of services provided.

This derives through comparatively low cost education, good utilization of skills and knowledge, decreased patient waiting time, and increased time spent with patients by practitioners. It has been demonstrated conclusively that practices which employ PAs provide more patient visits per $1,000 cost, better care and lower overall expenses than similar physician-only practices.

DEPLOYMENT

Unserved and underserved areas of our nation continue to experience problems associated with the inaccessibility of health care, despite the projected physician surplus. Physician assistant deployment data, gathered by the Association of Physician Assistant Programs, indicate that 26.3 percent of all practicing civilian PAs are located in communities with a population size under 10,000 and that an additional 36.8 percent of all practicing civilian PAs are located in communities with a population size of more than 250,000. Clearly, physician assistants continue to make a contribution to solving the problem of health care maldistribution by locating in underserved areas such as rural communities and large inner city areas.

UTILIZATION

Continued federal support of physician assistant educational programs is important because of the potential for increased utilization of physician assistants in extended care facilities, nursing homes, and as providers of home health care. In addition, because of PAs' patient education skills and increased time spent in patient counseling, they are able to play an important role in disease prevention and health promotion. Continued federal support will enable programs to further develop these aspects of their curricula and evaluate teaching methodologies for effectiveness.

Furthermore, advances in PA education, including enhanced skills in geriatrics, health promotion and disease prevention, and substance abuse counseling have elevated the importance of PAs as providers beyond an already significant role in the provision of health care. As health care leaders begin to acknowledge the importance of the patient's role in maintaining good health by observing good health practices, it is equally important to recognize those health care providers that are capable of providing the level of patient counseling services necessary for proper patient instruction to achieve this goal.

In today's health care market, we can not overlook those forces which will stimulate new demand for physician assistant services. For example, new federal initiatives to contain costs through the use of diagnostic related groups for determining reimbursement levels may, in the long run, increase the utilization of physician assistants as providers in hospital settings. Also, because prospective payment systems may result in early discharges requiring home health care services, nursing home rehabilitation and increased ambulatory care, the demand for physician assistant services can be expected to rise.

New federal initiatives notwithstanding, data collected by the Association of Physician Assistant Programs show that the utilization of physician assistants in hospitals and non-hospital ambulatory clinics has more than doubled over the past decade. Furthermore, the percentage of physician assistants employed in private solo practices and private group practices continues to remain steady. Clearly, the health care marketplace has demonstrated a continuing need for physician assistants to meet the health care needs of this nation.

FEDERAL SUPPORT OF PHYSICIAN ASSISTANT PROGRAMS

Currently 39 programs are receiving FY 84 federal financial support which covers only a portion of their total operating budgets. These programs are expending these funds for the first year of a three year grant cycle. The Bureau of Health Professions administers physician assistant grant programs which operate on a three year grant cycle. Grant requests are reviewed by a committee and are either approved or disapproved for funding based on that review. According to figures released by the Bureau of Health Professions, it has approved physician assistant program grant requests totaling $6.6 million for FY 85.

Because of reductions in federal support many programs have been forced to increase their tuition costs significantly, thereby preventing a segment of the population from entering the PA profession. Currently, physician assistant students come from a broad section of socio-economic groups. Information being collected from member programs of the Association of Physician Assistant Programs give us a preliminary indication that over 90 percent of PA programs are raising their tuition fees an average of 15-20 percent, in some part to cover reductions in federal support.

The institutions which sponsor physician assistant programs continue to demonstrate their support of these programs by absorbing the administrative costs related to providing access to existing medical education courses for physician assistant students. Physician assistant programs are divided equally among private and public schools. Given the financial structure of these two types of institutions, reductions in federal support more directly affect private institutions which do not have any recourse except tuition increases to maintain these programs.

It should be apparent that given the relatively high cost of physician assistant education, federal support has not contributed to subsidizing lower tuition fees, but rather has provided for improved quality of education for physician assistant students. Over the past decade of federal support for PA programs, a number of evaluative studies have focused on PA education to measure the effectiveness of programs in educating primary care providers. This evaluative process has led to number of innovations in medical education.

For example, PA educators have pioneered the use of clinical algorithms, patient management problems, computer-based clinical simulations, and patient instructors in their programs. Also, they have been innovative in the development of new teaching methodologies in clinical behavioral sciences and clinical interpersonal skills. Patient education, interviewing and history taking, health counseling, and preventive medicine are recognized within PA programs as integral parts of a comprehensive primary care education. Finally, PA programs have demonstrated how practitioners can be employed in medically underserved areas after completing educational preceptorships in those areas.

A unique and often overlooked aspect of federal support of physician assistant programs is the networking and sharing of information that occurs among programs. Many programs receive federal demonstration grant awards which enable individual programs to develop a particular aspect of program curriculum, a particular teaching methodology or evaluation tool. The results of these efforts are then shared with all member programs of the Association of Physician Assistant Programs which represents virtually all accredited physician assistant programs. This results in the most cost effective use of federal funds to enhance physician assistant education, deployment and practice.

Unfortunately, over the last five years, reductions in federal support for physician assistant programs have caused reductions in the nationwide physician assistant student/faculty ratio, thus preventing programs from offering the best possible education for PA students. Important aspects of educational evaluation are also eliminated as attempts are made to modify programs to meet the financial limitations imposed by reductions in federal support.

In FY 84 physician assistant program grant requests totaled $6.9 million. However, Congress appropriated only $4.7 million of the $6.0 million authorized. This level of funding has caused programs to increase tuition, curtail important educational projects, and reduce faculty and staff. All of these actions impact adversely on physician assistant education and the ability of the profession to fulfill its role as an important part of the nation's health care delivery system. For FY 85 we strongly urge that you appropriate the full amount of the anticipated authorization for physician assistant program funding.

Mr. WISE. I am not sure it is good being last, Mr. Chairman, but I will give it a try.

Senator BURDICK. You are the cleanup hitter.

Mr. WISE. Cleanup hitter. [Laughter.]

Mr. Chairman, I very much appreciate on behalf of the American Academy of Physician Assistants the opportunity to present our testimony, a copy of which you should have with you.

The academy is the national professional organization which represents physician assistants nationwide.

At present there is no official authorization for physician assistant programs. It is our understanding that the Senate Labor and Human Resources Committee, chaired by Senator Orrin Hatch, will introduce legislation that includes PA Program reauthorization at $5 million for fiscal years 1985, 1986, and 1987.

The House Energy and Commerce Health Subcommittee, chaired by Representative Henry Waxman, has not as yet determined what funding levels it will support for PA Program reauthorization.

However, we are confident that the Senate and the House will recognize the need for reauthorization of funding support for PA educational assistance, and we strongly urge the Senate Labor-Health and Human Services-Education Appropriations Subcommittee recommend continued appropriation for physician assistant programs at the level being currently considered by the Senate Labor and Human Resources Committee.

For fiscal year 1985, a minimum appropriation of $5 million is needed for physician assistant programs to continue to recruit, to educate, and to deploy physician assistant graduates.

For over a decade, Congress and past administration, Republican and Democratic alike, have supported physician assistants because of their potential for reducing health care cost and providing health care in underserved areas. The potential for cost savings in the provision of health care by utilization of PA's has never been more important than it is today.

As health care expenditures continue to rise on a national level, physician assistants offer the most significant means of reducing costs while maintaining the level of the quality of services provided.

This derives through comparatively low-cost education, good utilization of skills and of knowledge, decreased patient waiting time, and increased time spent with patients.

It has been demonstrated conclusively, for example, by studies that we have done, that practices which employ PA's provide more patient visits per $1,000 of cost, better care, and lower overall expenses than similar physician-only practices provide.

Unserved and underserved areas of our Nation continue to experience problems associated with the inaccessibility of health care, and despite the projected physician surplus. Our physician assistant deployment data and other national data gathered by the Association of Physician Assistant Programs indicate that 26.3 percent of all practicing civilian physician assistants are located in communities with a population size under 10,000 and an additional 36.8 percent of all practicing civilian PA's are located in communities of sizes of less than 250,000.

Clearly, physician assistants continue to make a contribution to solving the problems, we feel, of maldistribution by locating in underserved areas, such as rural communities and inner city urban areas.

Continued Federal support of physician assistant educational programs is important because of the potential for the increased utilization of physician assistants in extended care facilities, nursing homes, and as providers of home health care.

In addition, because the PA possesses patient education skills and spends an increased amount of time providing patient counseling, they are able to play an important role in disease prevention and health promotion.

Continued Federal support will enable programs to further develop the aspects of these curricula and to evaluate these new educational teaching methodologies for effectiveness.

Furthermore, new initiatives in PA education, including enhanced skills in geriatrics, health promotion, and disease prevention and subtance abuse counseling, have elevated the importance of PA's as provide beyond an already significant role in the provision of health care.

As health care leaders begin to acknowledge the importance of the patient's role in maintaining good health by observing their own good health practices, it is equally important to recognize these health care providers that are capable of providing the level of patient counseling services necessary for proper patient instruction and to achieve this goal of maintaining one's own good health.

In today's health care market, we cannot overlook those forces which will stimulate the new demand for physician assistant services. For example, the recent Federal initiatives using diagnostic related review groups for determining reimbursement levels may in the long run increase the utilization of physician assistants as providers.

New Federal initiatives notwithstanding, data collected by the Association of Physician Assistant Programs has showed that the utilization of physician assistants in small community hospitals has indeed increased, almost doubled.

Currently, 39 programs are receiving fiscal year 1984 Federal financial support which only covers a portion of their operating budget. These programs are extending these funds for the third of the 3-year grant cycle.

The Bureau of Health Professions administers these grants, goes through a review process. Grants are reviewed and either approved or disapproved, and the funding that they receive is based on their reviews.

Because of reductions in Federal financial support, many programs have been forced to increase their tuition costs in order to prevent closing their programs, but this, in fact, has prevented a segment of the population from being able to enter the physician assistant profession, although these same institutions continue to demonstrate their support of the Physician Assistant Program by absorbing administrative costs related to providing access to existing medical education courses.

Let me quickly summarize. It should be apparent that, given the relatively high cost of physician assistant education to the minorities—and Federal support has not, in fact, contributed to lowering those tuition fees but rather has provided for improved quality of education—the evaluative studies we have done have conclusively proven this.

I would quickly summarize by saying I think it is important also to note that the programs in existence share the funds that they have received by doing joint evaluation studies of the education they have provided and of where the graduates have gone and of the services that they have provided.

I very much appreciate the opportunity to testify.

Senator BURDICK. I am not as familiar with this program as I probably should be. Does a physician assistant work with a physician?

Mr. WISE. A physician assistant does work under the supervision of the physician by providing a greater accessibility for the physician to see a greater number of patients.

He can or cannot, for example, in some of the rural areas—offhand, like West Virginia—there are small clinics that can't support a physician's salary that are manned by physician assistants, and, in fact, the physician provides kind of a circuit riding approach to visiting these clinics 1 or 2 days a week, while the PA is actually providing onsite health care under supervision.

Senator BURDICK. In other words, a physician assistant would establish himself in a small town?

Mr. WISE. That couldn't afford a physician.

Senator BURDICK. And operate on his own power?

Mr. WISE. Not on his own power. He would have to have a method of supervision under State law.

Senator BURDICK. Well, is he an agent of the doctor?

Mr. WISE. He is an agent of the doctor, that is correct.

Senator BURDICK. And your fees, your compensation is billed through the fees that he might——

Mr. WISE. Yes; it doesn't increase the costs, Senator, because the fees remain the same. The way the physician is able to maintain the cost of a physician assistant is the physician, he or she, is able to increase the number of patients they see. So it is the volume of patients, the accessibility.

Senator BURDICK. The cost to an individual patient isn't increased?

Mr. WISE. That is correct, sir.

Senator BURDICK. No duplication?

Mr. WISE. Yes; that is right. It is actually— getting right down to it is it is taking an individual in a shorter period of time. That is why it costs less to educate physician assistants, providing them with the skills to do much of what a physician does, and that is—some studies have shown as much it is as much as 70 percent—to provide skills to patients under that physician's supervision, allowing the physician to use his 13 years of medical education to deal with more complex problems.

Senator BURDICK. Well, the physicians I **know** in my part of the country generally have a very proficient nurse available.

Mr. WISE. Well, nurse praticitioners——

Senator BURDICK. Now, you have got an office with a doctor and a nurse and an assistant. How do you assign your functions?

Mr. WISE. It really depends, sir, on how the physician utilizes the physician assistants and the skills of the office nurse versus the physician assistant.

The PA's, for example, in our program that we train at George Washington, are trained in more the diagnostic skills that physicians are trained in rather than more the caring skills that perhaps nurses are trained in.

I wouldn't contest for a second, though, that an office nurse who has been with a family physician for 20 some years wouldn't be providing much of the same skills. That, in fact, is a reality.

But it is the approach to training these individuals and giving them more of the basic diagnostic knowledge that a physician receives in medical school. In fact, they are oftentimes trained in tandem, such as an RN Program.

Senator BURDICK. Well, I know a lot of people are going to be concerned with having a doctor and an assistant and a trained professional nurse all in the same office because that might be reflecting higher cost to the patient.

Mr. WISE. Well, it doesn't if you look at the roles. OK, that is the issue, sir. Clearly, the PA has a role more akin to the physician's role, in dealing with the more common things that come into a practice than does the nurse, who really has more of a——

Senator BURDICK. Is the assistant an employee of the doctor?

Mr. WISE. That is correct.

Senator BURDICK. I see, just as the nurse is?

Mr. WISE. Correct.

Senator BURDICK. Well, thank you very much.

Mr. WISE. Thank you, sir.

PREPARED STATEMENTS

Senator BURDICK. Your statement will be included in the record as well as other statements submitted on the budget for Health Resources and Services Administration [HRSA].

[The statements follow:]

STATEMENT OF JACALYN WICKLINE RYBERG, RN, MA, CPNP, NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS

The National Association of Pediatric Nurse Associates and Practitioners (NAPNAP) is pleased to present written testimony supporting appropriations of the Nurse Training (Education) Act of 1984. NAPNAP is available to work with the Committee on Appropriations in developing and passing appropriations legislation pertaining to nurse practitioners and the Nurse Training (Education) Act.

NAPNAP is a formal professional organization that represents 2600 pediatric, family, and school; nurse practitioners. NAPNAP has been instrumental in defining the Pediatric Nurse Practitioner (PNP), developing a Scope of Practice, developing Educational Guidelines, and developing and implementing a national certification and certification maintenance procedure. The organization is also active in supporting and conducting nurse practitioner research as well as disseminating the research findings. Primarily NAPNAP addresses PNP issues relevant to education, practice, certification, professional development and research.

Pediatric nurse practitioners were the first educated nurse practitioners and have been in existence for about 20 years. By definition, a nurse practitioner is a registered nurse who has completed an educational program preparing him/her to provide primary health care. The formalized educational program meets ANA/AAP Guidelines and the curriculum includes preparation in development of clinical judgment and decision-making based on a specific primary child health care core. Pediatric nurse practitioners in the future will be registered nurses with a minimum of baccalaureate nursing degrees and nurse practitioner education either in formal continuing education or master's programs.

The educational preparation enables the pediatric nurse practitioner to provide nursing care in primary health care settings in collaboration with other health care professionals. While most practice settings are ambulatory care facilities, the PNP may also contribute to the delivery and continuity of health care services within hospitals and other acute and long-term settings.

PNP's are synonymous with safe, cost-effective, and quality primary health care. For instance, the actual appointment "show" rates, return visits, and immunization levels of consumers are higher in nurse practitioner clinics than in non-nurse practitioner clinics. What is it that encourages consumers to seek or return for care from nurse practitioners? Quite simply--their INDIVIDUAL needs are met through direct care, education, counseling, referral, etc. Cost-effectiveness and quality care has been well documented over the past five years. NP's have been credited with possessing detailed interviewing/communication skills which in themselves have been cost-effective by decreasing the needs for some laboratory tests and prescription medications. Since NP's are known to identify more signs and symptoms through detailed histories and physical exams, the cost-effectiveness is realized through early problem identification, resolution and prevention of further or future sequelae. Through early identification and resolution of health care concerns, consumers are spared unnecessary visits to the emergency room as well as unnecessary days away from school and work.

Cost-effectiveness touches the pockets of consumers, health care providers, insurance carriers, tax-payers, and the federal government. Cost-effectiveness of NP's in primary health care, health education, counseling and follow-up services has been well documented. Through follow-up care, consumers have reported a high level of satisfaction with nurse practitioner/consumer relationships.

Nurse practitioners are also concerned about their professional education and their competency of practice. This is reflected through NAPNAP members support of continuing education, certification and certification maintenance. Certification for PNP's is available through either the National Board of Pediatric Nurse Practitioners/Associates or the American Nurses' Association.

NAPNAP does support the concept of NP education occurring at the master's level. However, there must be some plan for financial support for those NP programs that have not yet been absorbed into the master's programs. It is much too costly to begin new educational programs when those that are in place can be assisted in meeting special needs of the nursing profession or becoming graduate programs in nursing.

Professional research expertise evolves from master's and doctoral preparation. There is a need for continued nurse practitioner research in educational and practice settings, but until nurse practitioners are master's and doctorally educated, nurse practitioner conducted research will remain sparse. Many of the existing research studies have been conducted by physicians or social scientists. Professionally, it is necessary for nurse practitioners to develop research studies to further document consumer benefits and the nurse practitioner contributions to the health care system.

The 1983 report by the Institute of Medicine, NURSING EDUCATION: PUBLIC POLICIES AND PRIVATE ACTIONS, stresses the need for the services of nurse practitioners and continued funding for advanced education for nurses. NAPNAP strongly urges the Committee on Appropriations and the Congress to pass a Nurse Training (Education) Act which strongly supports nurse practitioner education, practice, and research that will strengthen the health care system. Preparing health care providers that are safe and cost-effective in turn pass along quality and cost-effective care to the consumers.

Additionally, NAPNAP supports the Tri-Council recommendations for the Nurse Training (Education) Act; the appropriation levels, for Advanced Nurse Training, Nurse Practitioners, Nurse-Midwifery Education, and Professional Nurse Traineeship programs. Again, if NAPNAP can be of assistance in developing this important legislation, please contact us.

Several publications about nurse practitioners have been included with this testimony. Thank you for your assistance in introducing this important legislation.

PUBLICATIONS

1. THE PEDIATRIC NURSE PRACTITIONER - The National Association of Pediatric Nurse Associates and Practitioners
2. SCOPE OF PRACTICE - The National Association of Pediatric Nurse Associates and Practitioners
3. PHILOSOPHY, CONCEPTUAL MODEL, TERMINAL COMPETENCIES FOR THE EDUCATION OF PEDIATRIC NURSE PRACTITIONERS - The Association of Faculties of Pediatric Nurse Associates/ Practitioner Programs, Inc.
4. NURSE PRACTITIONERS: A REVIEW OF THE LITERATURE 1965-1982 - American Nurses' Association and National Association of Pediatric Nurse Associates and Practitioners
5. NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES & PRACTITIONERS/NATIONAL BOARD OF PEDIATRIC NURSE PRACTITIONERS & ASSOCIATES
6. NAPNAP FOUNDATION - National Association of Pediatric Nurse Associates & Practitioners
7. COST-EFFECTIVENESS/QUALITY OF CARE (Nurse Practitioners)-Bibliography

(Note: The publications are being held in the subcommittee files.)

STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) represents 361 college and university schools of nursing and approximately 8,000 full-time faculty. Our organization exists to improve the practice of professional nursing through advancing the quality of baccalaureate and graduate programs, promoting research; and developing academic leaders.

We appreciate the opportunity to submit testimony to this committee regarding the appropriations for nursing education under Title VIII and for nursing research under Titles III and IV of the U.S. Public Health Service Act.

NURSING EDUCATION

The intent of the Nurse Training Act which was originally authorized in 1965 was two-fold: to expand the supply of nurses, and, to improve the quality and distribution of nursing services provided to the public. Over the past 19 years, the basic nursing supply problem has been addressed, however, the second Congressional charge to improve quality and distribution of nursing services has not received enough attention.

It is time to focus on the issues of quality nursing services and adequate distribution of those services. We are now at a point in health policy where there is a critical need for nurses who are educationally prepared to deliver high quality, complex services, to organize and administer those services in the most cost effective manner possible, to research the outcomes and effectiveness of nursing services, and, to prepare the nursing educators. The AACN believes that continual federal support for graduate and baccalaureate preparation for nurses is essential to address these needs.

Institutional Support

Advanced Nurse Training. The IOM study emphasized the need for Federal support for advanced nurse education.

Nursing can be instrumental both in reducing health care costs and in providing quality health care services. However, this can occur only if schools of nursing are encouraged to develop and maintain graduate programs which will produce enough well-prepared nurse administrators, nurse educators, nurse clinicians and nurse researchers.

The scarcity of nurse administrators with advanced education is attested to by the National Survey of Registered Nurses in 1980 that reported that among the more than 61,000 RNs who occupied top nursing administrative positions, only 18% held a Master's degree and only 1.4% held a doctorate. Yet these nursing directors are responsible for departments that comprise at least 30% of the total hospital budget. The focus on cost containment and the change to a prospective payment system in our hospitals increases the need for nursing administrators with advanced nursing education that includes business administration, economics, budgetary management, and human resources management in addition to advanced clinical practice. Many Masters and Doctoral level nursing programs must revise their curriculums and expand their programs to speak to the evolving needs for nursing administrators, but cannot do so unless there is an increase in Federal support for the programs.

Nursing programs must also receive increased Federal support to meet the critical need for more nurse educators. Of the approximately 20,000 full-time faculty in all levels of nursing education in 1980, only 68% had a master's degree and only 7% held a doctoral degree. Among AACN schools, 24% of the faculty held a doctorate degree. The proportion of nursing faculty with doctorates does not compare favorably with other disciplines. A National Science Foundation study of science and engineering faculty found that more than 90 percent held the doctoral degree.

Additionally, constant changes in health care technology and advances in medical science have created extraordinary demands for the advanced degree nurse clinician who is able to provide direct patient services in acute care hospitals, community agencies and in long-term care settings. The IOM reported that the majority of university hospital administrators prefer masters prepared nurses for intensive care and other specialized patient units (p.43). Patients are sicker, and there are many more technologies which sustain life and therefore require close monitoring. Patients on dialysis, respirators, and hyperalimentation are increasingly being cared for at home and have nursing care needs which were once strictly limited to inpatient, acute care settings. The complexity of long term care has increased dramatically, both in terms of numbers of patients as well as the intensity of services required by this population.

The estimates of future supply contrasts sharply with the estimates of needs for nurses with graduate degrees that DHHS projected for 1990. Using the judgment of need (WICHE) model, the projected minimum need for master's degree nurses was an estimated 256,000. For doctorate degree nurses, it was an estimated 14,000. The IOM study projects that the supply of such nurses by 1990 would be considerably less than half those numbers (page 144).

State and local governments and the private sector simply cannot respond adequately or rapidly enough to address this critical shortage of nurse clinical specialists, nurse educators, researchers, consultants and administrators.

Therefore, a substantial increase in the Federal appropriation is necessary to enable collegiate schools of nursing to plan, develop, operate, expand, and maintain programs for the advanced education of these nurses at the master's and doctoral level.

Nurse Practitioners Programs. Included in this need for institutional support for advanced training is the need for increased Federal grants to collegiate schools of nursing for the education of nurse practitioners. The IOM study stressed the need for the services of nurse practitioners, especially in medically underserved areas and in programs caring for the elderly.

Even with the anticipated increases in physician supply, nurse practitioners will be needed to serve hard-to-reach populations, to facilitate new organizational arrangements for providing health care in cost effective ways, especially in practice settings that operate within fixed budgets, and to augment the quality of care provided in nursing homes.

In a review of 15 studies, J.C. Record concluded in a 1979 DHEW document that between 75%-80% of adult primary care services and up to 90% of pediatric care services could be performed by nurse practitioners. Potential cost savings with the use of nurse practitioners was $0.5 billion to $1 billion or 19%-49% of total primary care provider costs. If we are to contain health care costs, the use of nurse practitionrs to deliver high quality health care must be increased.

The trend for nurse practitioners to be educated in master's programs rather than certificate programs is supported by AACN. Since the nurse practitioner has a high degree of responsibility and automony, it is advantageous that they have advanced education.

Nurse practitioner grants should continue to include current, well-established programs in nurse midwifery. The high quality and cost-effectiveness of nurse midwives are repeatedly demonstrated in research findings.

We recommend an increase in the appropriations for grants to collegiate schools of nursing to plan, develop, operate, expand, or maintain programs for the education of nurse practitioners and nurse midwives.

Special Projects. Grants to schools of nursing are necessary to increase opportunities for individuals from disadvantaged and ethnic-minority backgrounds to enter the nursing profession. Minority groups in the population, including new immigrants, are particularly disadvantaged both in their access to health services and in their access to educational opportunities in nursing.

Special project grants are also needed to modify existing nursing education programs to provide opportunities for educational advancement, preceptor experiences, and for continuing education programs. Schools of nursing need special project funding to develop programs to minimize loss of time and money by students moving from one nursing education program level to another. AACN supports an increased appropriation for Federal grants to schools of nursing for special projects.

Student Support

Traineeships. To eliminate the critical shortage for nurses with advanced education, access to full-time study must be available to qualified individuals. Many Rns recognizing the need for advanced preparation do not have the resources to pursue full-time education. Compared to other health professionals, nurses often do not have the earning potential to pay off large loans. Therefore, traineeships for the education of nurses are necessary.

Student Loans. AACN supports rigorous, but fair, nursing student loan (NSL) collection to ensure that government dollars under this program are protected and that this very worthwhile and essential program is continued. In recent months nursing schools have made dramatic improvements in loan collections.

In spite of these improvements, the proposed regulations for nursing student loan (NSL) programs, if enforced, would discontinue the program in 80% of all nursing schools. This would have a devastating effect and would constitute a real threat to the supply of nurses. AACN members are confident that the intent of Congress would not be met by the proposed regulations and therefore we support statutory changes that would improve the NSL program and establish reasonable and achievable loan collection standards for nursing schools.

When a school with an established NSL revolving fund closes, is suspended from the program, or cuts its class size significantly, all excess cash from the NSL program reverts to the United States Treasury. We have recommended a statutory change which will allow such money to be re-programmed to other schools participating in the NSL program.

In addition to recommending a continuation of the revolving nursing student loan fund, we recommend an appropriation for the development of revolving funds in new schools of nursing or in schools that have not previously had a revolving fund. It will not be possible for these schools to be included unless there is an appropriation for the nursing student loan program.

NURSING RESEARCH

Since promoting nurse research is a priority of the Association, we were extremely appreciative when the FY/84 appropriation for nursing research was increased from $5 million to $9 million. This action has had a dramatic effect on the number of research proposals submitted to the Division of Nursing. During this past proposal review cycle, four times as many proposals were submitted by nurse researchers.

A substantial portion of the health care dollar is spent on nursing care. Yet, a very small proportion is spent on improving that care through nursing research. Only 1% of the National Research Service Awards distributed between 1977-82 were for nursing research. Between 1976 and 1981, nursing research was alloted only $5 million annually or .37% of the $1.7 billion budget for biomedical research. Of the greater than $4 billion which NIH received last year from Congress, less than $1.5 million (.004%) was ultimately allocated to schools of nursing.

The goal of nursing research is to facilitate the development of clinical nursing interventions which will improve health outcomes and contribute to the optimal delivery of care. The primary focus is on care as compared to other disciplines which focus primarily on cure.

The scope of nursing research includes, for example, studies to reduce the complications of hospitalization and surgery, studies to improve the prospects for high risk infants and their parents, studies of methods to alleviate anxiety, stress, and pain associated with illness or disability, and studies to facilitate the utilization of new technological developments in patient care. Nursing research also makes a special contribution by demonstrating how health care costs can be dramatically reduced.

Studies by I. Martinson, a nurse, demonstrated that home care nursing services for children dying of cancer resulted in more satisfaction for the children, parents, and siblings, while the daily cost of the care was about half that of hospital care.

The six-year study in New York City of comprehensive ambulatory maternity care shows savings ranging from $855 to $1,840 when compared to normal birth charges in 13 Manhattan Hospitals for a Medicaid population.

Runyan demonstrated that as a result of nurse practitioner services, hypertensive and diabetic patients had lower blood pressures, lower blood sugers, and fewer hospitalizations than the control group.

A recent summary of numerous studies on patient education demonstrated that patient education provided by nurses reduced length of stay postoperatively by 1½ days as compared to control groups.

Infection control practitioners (75% of whom are nurses) were proven effective in decreasing the occurence of hospital acquired infections in a recent research study. This is critical when one considers that currently in this country we have 2,007,000 hospital acquired infections per year, half of which are preventable, and that these infections result in 6,409,000 additional hospital days, for a total cost of one billion dollars.

The value of nursing research in improving patient care and demonstrating ways to contain costs without reducing the quality of care is indisputable. The fact that nursing research is currently underfunded is also indisputable.

SUMMARY

It is for these reasons that we ask this committee to provide reasonable appropriations for nursing research and nursing education. The IOM study recommended an $80 million appropriation for nursing research and nursing education. We respectfully request that this committee respond positively to this recommendation which was made by an interdisciplinary scientific committee on the basis of a two year study.

We believe that an appropriation consistant with the IOM study recommendation would represent a small investment for a large return on the health care dollar.

Thank you for this opportunity to present our views to this committee.

LETTER FROM THE REGIONAL OPERATIONS FOR FACILITIES ENGINEERING AND CONSTRUCTION STAFF, REGION VIII

May 23, 1984

Department of Health & Human Services
Regional Operations for Facilities
Engineering & Construction, Region VIII
1961 Stout Street, Room 1152
Denver, Colorado 80294

The Honorable Lowell P. Weicker
Chairman, Subcommittee on
Labor, Health and Human Services,
and Education Appropriations
United States Senate
Washington, D.C. 20510

Dear Mr. Weicker:

In our letter of April 16, 1984 we respectfully urged your support for the continuation, intact, of all ROFECs (Regional Operations for Facilities Engineering and Construction) DHHS in the ten Federal Regions stating the reasons for our request and the consequences if the implementation of the recommendations of the Grace Commission Report were consummated. Some of these consequences have now arisen. We cited the purpose for which ROFECs were created and the enclosed Attachment identified some of the Federal Departments and Agencies whom we serve and who, with our abolition, would be required to fund and duplicate staffs, and establish or abandon the crucial responsibilities that were ours Further stating, that with the abolition of the ROFECs and the restructuring of the responsibilities, that the rights of the constituents to Federal services in the Congressional Districts in all regions in both urban and rural areas and the authority of Congress to authorize them would be negated.

Each region has its unique needs, conditions and responsibilities. The ROFEC organizations as they now exist have fulfilled them efficiently and with the greatest economy of costs, whether it be in response to the diverse needs based upon ethnicity such as Native American and immigrants (such as refugees), the universal needs for health and education, or responding in times of national emergency to the destruction caused by tornadoes, hurricanes, earthquakes, and floods.

We emphasized that the proposed reassignments of the ROFEC functions could only result in increased costs, the duplication of staffs, and the loss of exceptional technical services approximating centuries of professional experience. Now with the implementation of the Grace Commission recommendation by the Office of the Secretary our analysis is being verified.

In October 1983, the total number of ROFEC personnel was 150, and since then it has been estimated that this has been further reduced to 130.

It is now our understanding that the 1985 budget request of IHS (Indian Health Service) includes a request for funding approximately an estimated 80 positions for the employment in the Area Offices; in addition another 30 positions are being recruited for IHS Station Offices under the 1984 budget. These 110 positions involve contracts up to $200,000 identified for maintenance, repair, and/or alteration construction. The PHS contemplates funding 44 positions to be assigned responsibilities for IHS construction projects exceeding the $200,000 limitation. This represents the projected needs now envisioned by only one Agency for whom ROFEC now furnishes the architectural/engineering services.

The preceding combined estimated total workload requiring 154 FTE, (which exceeds the estimated existing staff of 130 ROFEC FTEs) is currently being accomplished nationwide by approximately 55 ROFEC FTEs. Excluding all other required architectural/engineering responsibilities, the above projected needs alone justify the continued existence of all ten ROFEC offices thus saving the funding for approximately 100 new positions.

ROFEC also furnishes the same services to the Department of Agriculture, FMHA, and other Agencies. (See Attachment). As GAO has already verified, the economic assumptions of the Grace Report are not valid.

We request that members of the Congress conduct a study independent of the Office of Secretary, PHS, or of the data furnished by the Grace Commision, the RASCs, and others thus far consulted as applicable to the destruction of the ROFECs.

In a letter dated July 12, 1983 addressed to "HHS Associates", the Secretary HHS states, "We are the people department, and people need our help now ". urging the staff to contribute desperately needed blood donations, concluding with the statement, "The credo of the Health and Human Services Department is 'We Care'. Let's translate our credo into action...".

We the civil servants, ("HHS Associates"), whose Agency in its entirety is to be abolished, have always fully contributed and continue to contribute both blood and knowledge and intelligence in solving the problems and meeting the needs of the constituents throughout the Congressional Districts. Having without reservations and under all circumstances fulfilled our responsibilities and in the process saved the taxpayers millions of dollars of expenditures, it now is incomprehensible that we, the professional staffs and supporting personnel in the existing ten ROFECs who initiated and established the necessary close rapport with the constituents in the Congressional Districts, were never consulted during the decision making process that now not only destroys that vital, personal caring relationship but, as contemplated under the aegis of a new structure, makes isolated and far removed geographically the drastically reduced participation in fulfilling the crucial needs of the public.

We again respectfully request your support for the continuation intact of the ROFECs/DHHS in all ten Regions, to which we have given our loyalties, contributed our knowledge, abilities, and years of service.

We request that this letter be made part of the record of any hearings held by Congress in regard to these matters.

Sincerely yours,
The ROFEC Staff, Region VIII

Region VIII Staff

Raymond B. Eakle	Raymond B Eakle
Patricia C. Gibson	Patricia C. Gibson
Robert I. Haught	Robert I. Haught
Elwyn Holtrop	Holtrop
Ralph E. Kelley	Ralph E. Kelley
Kenneth E. Kellogg	Kenneth E. Kellogg
Jerry D. McKinney	Jerry McKinney
Robert P. Merritt	Robert P Merritt
Vern Monroe	Vern Monroe
Robert D. Pearson	Robert D Pearson
Granville K. Peterson	
Ada Segal	Ada Segal
Richard Snapp	
Barbara J. Tamburelli	Barbara Tamburelli
Kurt E. A. Vragel	

ATTACHMENT

Among Federal Departments and Agencies impacted under the recommendations of the Grace Report, that are now served by the ROFECs who with our abolition will be required to fund and duplicate staffs, and establish, expand or abandon these crucial responsibilites are the following:

1. The Department of Agriculture. FMHA - Hospital and Clinics.

2. Indian Health Service. Hospitals, Clinics Housing, and Solar Design. Also, under P.L. 93-638 Indian Self Determination Act, ROFEC negotiates leases with Indian Tribes for the Indian Health Service, and the ROFEC Contracting Officer signs the leases.

3. Public Health Service. Hospitals, Clinics, HMO's, Fire Safety Consultation.

4 Social Security Administration. Surveys and planning of facilities.

5. Office of Civil Rights. Surveys and planning to assure compliance with Public Laws governing compliance with the Physically Handicapped Accessibility Standards.

6. Indian Preference Act. Contracts for architectural/engineering services and for participation in the bidding process of construction.

7. Small Business Administration. The development of contracts with small and disadvantaged businesses. A worthy socio-economic service.

8 Federal Emergency Management Administration. In addition to normal duties ROFEC architect/engineers are constantly tasked in National Emergencies such as earthquakes, floods, and tornadoes to perform surveys of damage and to provide engineering recommendations. Quite often the magnitude of the task requires the joint participation of ROFECs of several regions as occurred in the tornadoes originating within the Midwest the hurricane disasters in the Caribbean, and floods in the West and Southwest. On one occasion simultaneous tragedies, involving floods in Texas and nursing home fires in Massachusetts required ROFEC's immediate attention.

9. U.S Department of Labor Office of Federal Contract Compliance Programs. Equal Employment Opportunity and violation of labor laws.

10. Surplus Real Property Program. The disposal and recovery of land and buildings (often running into millions of dollars per transaction) requiring ROFEC appraisal and recommendations.

11. Recovery under the Hill-Burton Act (grants, loans, and loan guarantees for construction and modernization of hospitals and other medical facilities) generally involving millions of dollars requiring ROFEC appraisal and recommendations.

12. U.S. Department of Education. Elementary, secondary, higher academic facilities and college housing. ROFEC provides contracting services on Direct Federal facilities, and architectural/engineering reviews and supervisory approval. Federally Assisted facilities require the supporting services now only available in ROFEC.

STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) appreciates this opportunity to present its views to the Committee on FY 1985 Appropriations for the Departments of Labor, Health and Human Services, and Education. The AAMC is submitting this statement as a complement to a previously submitted statement containing its views on desirable levels of federal support for the NIH and ADAMHA's biomedical and behavioral research activities. This statement will principally cover the Association's views on federal backing for health manpower and related education programs but will also address other germane activities that receive funding through the bill.

Student Financial Assistance

Securing adequate support for student financial assistance is one of the AAMC's top three priorities. In 1983, the average medical student graduating with debt--some 86% of all M.D.s--owed $23,914. This figure has risen by over 73% in just 5 years. The unprecedented levels of debt for these graduates underscores the extent to which medical students are dependent on outside sources, particularly the federal government, for financial assistance. The aggregate need of medical students is further increased by the commitment of most medical schools to matriculating student populations reflective of the composition of the entire society. Fortunately, the federal government has set similar goals of promoting access to, and diversity within, medical education, and a number of programs have been authorized to accommodate the variegated needs of the potential medical school population.

Unfortunately, the student aid programs authorized under Title VII of the Public Health Service Act (PHSA) currently are substantially underfunded. The authorization ceilings for these programs were cut sharply in the 1981 Budget Reconciliation Process and they have lost even further ground in succeeding years. The Title VII student aid programs are now in the process of being reauthorized and although there are many other pressing issues vying for Congressional attention, the AAMC hopes that the reauthorization process will supply these programs with a much-needed vote of confidence and re-emphasis. The Association, in the context of its reauthorization proposal (and the appropriations process), is requesting the following funding levels for FY'85:

- $20 million for the Health Professions Student Loan (HPSL) program. This figure, while substantially higher than the extremely low appropriations of the past two years, is still very much needed and justifiable. Once medical students have availed themselves of Guaranteed Student Loans their only substantial source of relatively inexpensive loan capital is the HPSL program. These loans have the key feature of not accuring interest while a student is in school. Once a student has received whatever his institution can spare him from its HPSL revolving fund, he must turn to HEAL loans; and the latter loans, regardless of their regrettable necessity in an era of extremely high medical school costs, wreak havoc with students' attempts to avoid troublesome, preoccupying levels of debt. The apparently high delinquency rates have been reduced, dropping from 11.34% in 1980-81 to 7.83% in 1982-83; the latter figure is well below those in many other student loan programs. Moreover, the prevailing method for computing delinquency overstates its magnitude, if traditional banking standards are used as norms. The HPSL revolving fund is not as large as many assume--the approximately $22.4 million that was available in 1982-83 for over 60,000 medical students would have yielded only about $350 per student, if equally distributed among eligibles; actually, the average loan was $2,403, clearly well below what many beneficiaries needed to avoid turning to HEAL. Thus, the Association emphatically urges the Committee to reverse the disturbing funding trends for this program and give it a much merited and needed boost. Further underfunding of the program will undoubtedly lead to still higher student indebtedness.

- In accordance with its reauthorization proposal, the AAMC recommends that the Exeptional Financial Need (EFN) program be funded at a level of $8 million for medical schools alone. This figure will permit each medical school to grant five scholarships to its students and thereby make the program a meaningful source of funding for extremely disadvantaged students. In the rather emaciated current state of the program, less than two scholarships on the average are granted at each institution. The entire line-item might adequately be funded at a level of $13 million.

- The Health Education Assistance Loan (HEAL) program should be given a credit ceiling equal to its authorization level; the AAMC is requesting $275 million for FY '85. Usage of the HEAL program has increased dramatically in recent years--in the very short span of the 1980-81 school year to the 1982-83 award year, HEAL borrowing increased almost 200% for medical students--and there really is no telling how high demand could go. The AAMC is concerned that medical students are relying on the program so heavily, but, as mentioned earlier, there oftentimes is no alternative to these extremely costly loans, which accrue interest while a student is in school. In light of this reality, the program should be permitted to operate at its full authorization level. HEAL requires no federal outlays and, by virtue of its size, cannot, as the Administration has claimed, have an unfavorable impact on the overall allocation of credit in the country.

- The National Direct Student Loan (NDSL) program in Title IV of the Higher Education Act badly needs a funding boost. The authorization level of $286 million would be a reasonable level. NDSLs are a small but important source of loan money for very needy medical students.

Educational Initiatives

In recent years, the federal government has created and funded a number of educational programs designed to reverse undesirable trends towards physician subspecialization and location in more affluent sections of major metropolitan areas. It has been commonly agreed that these programs, which support institutions as well as trainees in specific areas, have been very effective in meeting their goals. But, to fully meet their objectives, ongoing support is needed. The AAMC thus recommends that:

- Grants to provide family medicine residency and training programs, outlined in Sec. 786 of the PHSA, be funded at $40 million.

- Programs for support of Departments of Family Medicine in Sec. 780 of the PHSA be funded at $15 million.

- Grants for training, traineeships and fellowships in general internal medicine and pediatrics (Sec. 784) be funded at a level of $20 million.
- Residency programs in preventive medicine (Sec. 793) be funded at $3 million.
- Two key educational initiatives be funded: the authority for grants in geriatric medicine (Sec. 788(d)) at a level of $25 million; and grants for the development and application of computer technologies in the academic health center (Sec. 769(a)) at a level of $15 million.
- Finally, the Disadvantaged Assistance Program in Sec. 787, which has proven extremely effective in enhancing the matriculation and retention of needy students, be funded at a level of $30 million.

Institutional Assistance

The major program in this area provides grants and loans for the construction of teaching facilities and laboratories. These authorities (Sections 720-726) have not been funded since FY 1978, but increasing public, institutional, and Congressional focus on the obsolete and decaying state of many laboratories and facilities, as well as the existence of a number of recently completed and ongoing studies on this subject, make it clear that the need for such investments is very strong. The AAMC thus urges that these critical initiates be undertaken once again, at a total funding level of $25 million.

Also, the financial distress grants and advanced financial distress assistance program (Sec. 788A and B) should be funded at $10 million.

The Association supports the Prospective Payment Assessment Commission (Pro-PAC) and urges the committee to appropriate adequate funding for the Commission. Staff of the Pro-PAC have estimated that it will need just over $3.1 million for FY 1985. This figure appears to be a reasonable, perhaps even a conservative estimate, of what this Commission will need in order to adequately perform the difficult duties with which it is charged.

While most parties involved in the health care sector have focused attention on the problems experienced during the initial implementation of the Prospective Payment System, important questions for assuring the long-term success of this system remain:

- At what rate should the DRG prices be increased in each year in order to reflect changes in inflation, productivity, technology, and quality?
- How should the DRG payment rates be changed to reflect improvements in both the practice of medicine and the ability to identify patient characteristics that influence the care rendered?

It is these two questions for which the Pro-PAC is responsible. It is vital that your committee continue to provide adequate funding for its functions.

SUBCOMMITTEE RECESS

Senator BURDICK. The hearing is recessed.

[Whereupon, at 12 noon, Thursday, April 12, the subcommittee was recessed, subject to the call of the Chair.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1985

TUESDAY, APRIL 24, 1984

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker, Hatfield, Rudman, Specter, Proxmire, and Burdick.

NONDEPARTMENTAL WITNESSES

STATEMENT OF HON. JACOB K. JAVITS, FORMER SENATOR FROM NEW YORK

ACCOMPANIED BY DR. FRED PLUM, NEUROLOGIST

Senator WEICKER. The subcommittee will come to order.

Today we will be hearing from public witnesses on the National Institute of Neurological and Communicative Disorders and Strokes, the National Institute of Allergy and Infectious Disease, and the National Institute of Arthritis, Diabetes, and Digestive and Kidney Disorders.

Our first witness this morning is a dear friend and—I say it publicly. I hope he doesn't deny it—my mentor as far as matters before the U.S. Senate in so many areas. Jack Javits' career of public service has never stopped, and nothing proves that more than his appearance before the committee today.

I note that Senator Javits brought with him Dr. Plum, so, Jack, why don't you proceed in whatever way you choose, and go ahead and introduce your colleagues.

Senator JAVITS. Thank you very much, Mr. Chairman.

As the chair knows, I have brought with me perhaps the No. 1 neurologist of the United States to help in this testimony. I would like to make a brief statement myself and then introduce Dr. Fred Plum to the committee.

I appear today as a witness to testify in support of appropriations for the National Institutes of Health and specifically for the NINCDS, which is concerned specifically with neurological and neuromuscular diseases.

Interestingly enough, this is sort of a fourth career for me. I had one as a trial lawyer in New York for many years, then one in the Army as an officer, and then one in public service for many years, and now I appear as one who is himself afflicted with one of these diseases, and I feel it my responsibility, and with my wife, who has wonderfully joined me, to help the thousands who are afflicted by these diseases.

There are many voluntary organizations who are also at work in the effort to be of help. I, myself, am the director of the National ALS Foundation, and the executive director of the foundation is present here this morning.

There are many, many thousands of victims, and they all, I know, are here in spirit as are their families and friends.

The organizations to which I have referred, which includes muscular dystrophy, a very active one because of their annual telethon; many others are consolidated in an organization called the National Committee for Research in these diseases, and they will be appearing here to support generally what I plead for and what they plead for, which, in essence, is I know that you must work with various interests, that you must balance.

This is why we come before you, because in this particular field of research we all believe—the professional and the layman and the patients like myself—that we are ready for a big breakthrough as we have engineered one in respect to heart and as we have engineered one in respect to heart and cancer, beginning with the years, many years, that I spent as a legislator in the same endeavor.

This particular subcommittee is wonderful in its attention to this problem and in forwarding the effort to attain this breakthrough and bring nearer the day when, like the great strides in dealing with heart disease, cancer, and even one of the great neurological diseases like polio, we may crack the riddle of these diseases.

Dr. Plum, I am sure, will address what exactly the riddle is and how he thinks from the professional side we may hope to crack it.

My own career encompassed the first effort, one of the great efforts, in respect to heart disease, beginning in 1947, when I sought the establishment of an institute for that purpose.

We are all familiar with the concentration of resources on cancer and the heart in the early 1970's, continuing to this very day. But interestingly enough, those who suffer from what I am here to assist may properly be called as contrasted with those who have tragically died because of our beginnings in respect of the diseases of the heart and cancer.

In contrast with them in this field, we deal with the living dead, men and women, who due to muscular and neuromuscular and neurological diseases like my own, ALS, Alzheimer's, Huntington's, muscular sclerosis, muscular dystrophy, et cetera, are progressively and profoundly disabled and continue relatively long lives, but long lives which in many cases are lives of intense suffering and intense disability.

The responsibilities imposed on communities, on families, and on the individuals themselves are enormous, and especially when there seems to be little hope at the end, and yet there are tremendous personalities who are an inspiration to these thousands. Hundreds of thousands are themselves leading creative and productive lives, notwithstanding their great disabilities.

Now, I am a very real case in point because I have personally experienced these problems and personally experienced the treatment for them.

For example, with respect to my own disease, the first ray of hope of any relief whatever has some in a drug called thyrotropin, a repeating hormone, the use of which is now spreading throughout the United States, which gives some promise where there was no promise before, and its development is heavily attributed to the work of voluntary organizations, including the National ALS Foundation and the Muscular Dystrophy Association, and now I think will be much promoted by the added resources which this committee has afforded to the profession in a manner which has been tremendously generous and tremendously helpful.

To indicate the future—and I will not detain the committee for very long—I would like to read one paragraph, very brief, of a report prepared at the request of the Appropriations Committee of the House and Senate late last year, which indicates that this effort, tragic in its implications, deserves at this time, because of the state of scientific progress, the support of the Nation through the Congress. This excerpt from a report which is dated October 1983 reads as follows:

> The prospect for understanding the functions of both the healthy and the diseased human brain in the exact terms of the neuroscientist has never been greater. Truly, we are entering a new era, a decade of brain research in which prevention or repair of neural disorders becomes a real possibility and in which every human mind may eventually realize its full intellectual and emotional potential.

This is essentially the theme that I am bringing to you this morning. The real key to finally dealing with the riddle of these neuromuscular and neurological diseases will be basic research. Of that I am deeply convinced.

This, however, in my opinion, may not be construed as a parochial effort. Neuroscience, I am advised, cuts across all scientific lines, and whichever of these are necessary to crack these riddles should be supported.

Now, to summarize, what I have to recommend as a patient and as a thoughtful American who has dealt with these problems for decades as a legislator, I come to these conclusions, which I urge upon this subcommittee.

First, the interdisciplinary impact of research in the neurosciences as it has developed due to the enhanced opportunities afforded scientists and doctors by the enhanced appropriations made available by the Congress are most promising from the patients' point of view.

Second, the possibilities exist today as they did a decade or two ago for heart and cancer in this particular field.

And, third, I believe this promise may best be realized in giving the example of TRH in respect to my own particular illness, incidentally developed by a gifted researcher and doctor who was once in the NIH itself, Dr. W. King Engel from southern California and now the use of which has spread throughout the United States. As a direct result of that we are in a breakthrough situation.

I suggest to the committee that it consider what technique to make a hallmark in this breakthrough possibility. We have used various techniques which should be considered again, and where the appropriation is committed it may itself be the instigator.

For example, the report from which I read was prepared by a think tank operation at the request of the Appropriations Committee.

I gather it is a further fact that in the respect of cancer, you will recall, at the instigation of Congress a cancer panel was appointed which functioned with laymen; as chairman a man named Ben Oshman of New York, and he gave leadership, experience, balanced judgment which resulted in tremendous progress.

I respectfully submit that you might think about and develop such an aid to the national effort. I urge you to work it out as an extension of your oversight responsibility so that the panel will—whatever other technique you decide on—report directly through to you. This is an added function to the work which is done in the NIH by its Director, Dr. Wyngaarden, and the official in charge of this particular institute, Dr. Murray Goldstein.

I close with this thought: That the time and the opportunity are here; that you have recognized in the appropriations in fiscal year 1984; that you fortify this recognition by what you do in 1985 and the years after that.

In this particular field, the future is promising if you continue to give it the support so well-recognized in your appropriations.

In fiscal year 1984, the plans include an extension of research project grant support to a select group of senior investigators for longer periods than have heretofore been afforded, an increase from 4 to 7 years. They include a great increase in the number of clinical investigators with limited research experience who now can be brought into the field and the scholarships for this purpose which the committees of the House and Senate graciously authorized in my name.

Now, we come to another great possibility, all very much in accord with the procedures of the NIH, and that is the possibilities inherent in groups of investigators and scientists who are maybe now available for the purpose of enhancing the possibilities of a breakthrough in respect of these diseases.

The NIH plan calls them centers of excellence, and this seems to be the next step which you should hopefully contemplate in the appropriations for fiscal year 1985.

And I hope very much that the living dead—my term—who are afflicted with these neurological and neuromuscular diseases may now see real promise and new hope from what you have already done in 1984 and from what you will do in 1985.

I cannot begin to tell you what a ray of light this will mean to thousands of victims and the thousands of families who have seen practically no hope before and now, with what you have done and can do, will see new hope and new opportunity.

Thank you, Mr. Chairman.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Jack. We will insert your statement in the record before we ask you a few questions.

[The statement follows:]

STATEMENT OF SENATOR JACOB K. JAVITS

I appear today as a witness to testify in support of appropriations for the National Institutes of Health specifically for the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). I hope to present a view which may be of help to the thousands afflicted with these diseases like I am myself afflicted with one of them, amyotrophic lateral sclerosis (ALS) also popularly known as Lou Gehrig's Disease. There are many voluntary health organizations in respect of these diseases in our country which are doing splendid work in stimulating research and greatly assisting in patient care. I am, myself, a director of one of them, the National ALS Foundation, Inc. and I have worked with the Muscular Dystrophy Association and many others. They have also combined in the National Committee for Research in Neurological & Communicative Disorders in the effort to get adequate appropriations for research in this field. The NCR will be appearing before this Subcommittee as well.

I can report that I find an admirable common purpose among all these private voluntary organizations in their dedication to results in finding causes, cures and means to ameloriate the suffering of those afflicted. You have given enormous encouragement to all of these patients and to their families by the enhanced appropriation in the sum of about $38 million, an approximately ten per cent increase in fiscal year 1984 over fiscal year 1983. You have helped bring hope where there has heretofore been little hope and to bring nearer the day when like the great strides in dealing with heart disease, cancer and even neurological diseases like polio we may crack the riddle which these neurological and neuromuscular diseases have presented up to now. Also, I would like to thank my former colleagues in the House and Senate for the honor they have given my family and me in linking my name with this effort.

It is vital to note that we are dealing here with a subject of grave human consequence. All of you will recall the determination which began in the late 40's and came to fruition in the 60's and early 70's that we were determined to reduce the toll of mortality of victims of heart disease and of cancer. As a Congressman and a Senator I had the inestimable privilege of being myself a party to these efforts in which voluntary organizations were of great help.

But now we come in the neurosciences to a field which deals with the "living dead" -- men and women who are disabled by our failure as yet to crack the riddle of neuromuscular and neurological diseases like my own ALS, Alzheimer's disease, Huntington's disease, Multiple Sclerosis, an estimated total of forty such diseases, men and women who live for varying periods of time but who are progressively and profoundly disabled by these diseases while alive. They impose tremendous responsibility on the communities and on the health facilities of those communities in which they live putting a grave strain upon their families and friends and not only upon their own physical but also upon their financial resources and their resources of spirit and determination.

There are hundreds of these cases among men and women who are an inspiration to the thousands who suffer because at the same time they continue to lead creative and productive lives notwithstanding their great disabilities.

The scientists and the doctors tell us that we are now ready for a breakthrough in this field. I would like to quote for you one paragraph from a report dated October, 1983 developed in response to a request of the Senate Appropriations Committee in connection with appropriations to NINCDS for fiscal year 1983 on the research opportunity and the research needs for this Institute. This report was commissioned by the NIH and used the input of a panel of twenty-five experts in the basic and clinical neurological and communicative sciences to assess the status and needs for research in these areas. The last paragraph of the Introduction bearing the title: The Neurosciences: An Explosion of New Methodologies, Opportunities, and Challenges reads as follows:

> "The prospect for understanding the functions of both the healthy and the diseased human brain in the exact terms of the neuroscientist has never been greater. Truly, we are entering a new era, a decade of brain research in which prevention or repair of neural disorders becomes a real possibility and in which every human mind may eventually realize its full intellectual and emotional potential."

This is essentially the theme of my testimony today. This is the basis of the managerial responsibility carried by Dr. James B. Wyngaarden, director of the NIH, and Dr. Murray Goldstein, the director of the Institute most directly affected.

I shall hope to lay before you several important issues:

1. The interdisciplinary impact of research in the neurosciences as it has developed due to the enhanced opportunities afforded scientists and doctors by the enhanced appropriations made available by the Congress.
2. The promising nature from the patients' point of view of the plans for enhanced research in this field made possible by the enhanced appropriations provided by the Congress for FY 1984.
3. My own thoughts on how to best coordinate this breakthrough effort using as a model the effots which have brought about such important breakthroughs in the two leading killers: heart disease and cancer are as follows:

> As one example from my own personal experience, I have had tested out on me a drug, TRH, which gives some promise of relief to those afflicted with ALS. Its use was first proposed by Dr. W. King Engel now of the University of Southern California and the Hospital of the Good Samaritan in Los Angeles, who himself worked in the NIH when I first met him at the end of 1979. The use of TRH has also enlisted other researchers, among them: Dr. Theodore Munsat of the New England Medical Center in Boston, and Dr. Melvin Yahr and Dr. James Caroscio of Mt. Sinai in New York, by whom I have been treated personally as I have by Dr. Engel. It is the first drug to come along that seems to have promise. Within the last two or three years and with the cooperation of the Food and Drug Administration its use for research purposes has now spread throughout the country and different modes of administration have been developed. I believe its future is very promising and in the meantime it is the only game in town. But the big point is: Where there was nothing before there is now something.

I would urge upon the Appropriations Committees of the House and Senate that based upon this record and these experiences they consider some special mechanism, such as a special committee or panel on a very high level to report to both Appropriations Committees within an appropriate period of time assessing the progress made to date and the future of neurosciences research. Such a report could be of tremendous value both to the Congress and the nation.

I would close by emphasizing the time and the opportunity. The outline of the utilization of the enhanced appropriations for FY 1984 as reported by NINCDS are very instructive and may be very promising in this regard. The plans include an extension of research project grant support to a select group of basic and senior neuroscience and communicative science investigators for a period of up to seven years -- contrasted with the present four years -- to select investigators who have demonstrated qualities. A great increase in the number of clinician-investigators with accommodation for the different needs of the "selected clinician with limited initial research experience, the physician with demonstrated research potential and the M.D.-PhD. younger researchers who can be drawn in to concentrate on this field. NIH has done me great honor pursuant to the report of the Appropriations Committees of the House and Senate on the 1984 fiscal year appropriation of naming these the Senator Jacob K. Javits scholars in the neurosciences.

There is added to these efforts another which is of the most vital importance and may be, indeed, the critical mass involved with the whole breakthrough effort and that is what the NIH calls their Centers of Excellence to provide stable support to a select number of teams who have the promise of being able to advance the cutting edge of neuroscience. Their purpose is to "explore conceptual issues of future significance".

Considering the NIH procedures involved and the great promise of this effort -- which is not unanalagous to the breakthrough of Dr. Jonas Salk in respect of polio -- there looms before us a great objective for FY 1985. I hope very much that this promise will not be denied to those whom I call the "living dead" -- the victims of neuromuscular and neurological diseases. A promise long awaited and now hopefully within sight. And, that the Congress will at least repeat the appropriations for NINCDS for fiscal year 1985 which it granted for fiscal year 1984.

Senator WEICKER. One question. I would like to have Senator Proxmire and Senator Specter have the opportunity to ask questions.

Are you and your colleagues with the administration request for funding for NINCDS, or is there a specific amount that you feel should be raised?

Senator JAVITS. The committee was wonderful in fiscal 1984 in raising the appropriation, in round figures, about 10 percent. The experts from whom I quoted thought that the right figure, considering the opportunity in this particular field should be $500 million, in round figures. You provided some $338 million in that amount.

My own feeling is at the very least, considering the constraints of the budget, that that figure should certainly be continued for 1985 so that these plans may go forward and I think, if at all possible, they ought to be increased again by approximately a similar percentage on the grounds that the breakthrough possibilities here are now so real that, as you did in other years in cancer and heart, this area deserves a concentration of your effort.

That would be my conclusion.

Senator WEICKER. Thank you very much.

Senator Proxmire.

Senator PROXMIRE. Jack, it is wonderful to see you. The only reason I am here is because you called me and told me to get to the airport and get here.

I can tell you I have been in the Senate 27 years, and in all that time there has never been a Senator as intelligent as you, with as much integrity and as much knowledge in as many fields as you have.

Your testimony this morning is extremely enlightening and useful to this Senator, I can tell you. The question asked by the chairman related to how much the Institute should have in the coming year, and I am inclined to agree with you that there ought to be another 10-percent increase in view of the need.

As I understand it, the National Institute of Neurological and Communicative Disorders and Stroke has a budget which is less than one-half of the Heart Institute's budget and less than one-third of the Cancer Institute's budget. You say we are entering an era of new developments in the prevention and repair of neural disorders. I can't think of anything that would be more encouraging, whether we have this problem in our families or not, than to make the kind of advances we can expect if we make this kind of investment.

So I want to thank you for superlative testimony. Just your presence here makes a world of difference for us.

This is a moment I will never forget in my life.

Senator JAVITS. Thank you so much, Senator.

Senator WEICKER. Senator Specter.

Senator SPECTER. Thank you very much, Mr. Chairman.

I have no questions, but I would comment that seeing you here, Senator Javits, is quite inspirational. I have had some contact with a triple sclerosis, and I have discussed the matter with you and Mrs. Javits and the doctors with whom you are working.

I certainly would support the request which you have made this morning, and you have all of the vantage points to provide very weighty testimony, which I certainly do accept.

Senator JAVITS. Thank you, Senator. Thank you, Mr. Chairman.

Now, Mr. Chairman, with the permission of the committee, I would like to introduce one of the most eminent neurologists in our country, perhaps the world, Dr. Fred Plum, from New York.

PREPARED STATEMENT

Senator WEICKER. Dr. Plum, welcome before the committee. We are going to include your testimony in its entirety in the record.

[The statement follows:]

STATEMENT OF DR. FRED PLUM

Ladies and Gentelmen: I greatly appreciate the gracious invitation to testify before your committee and especially value the honor of sharing the morning with Senator Javits, whom I know both for his unfailing commitment to human welfare and his remarkably courageous fight in meeting the limitations of severe neurological disease. As you may know, I am Professor of Neurology at Cornell University Medical College and director of the neurological services at the New York Hospital in New York City. For a period that now extends for more than 30 years I have been directly engaged in patient care and research on neurological diseases, especially research on stroke and associated disorders of brain dysfunction. During this time I have had the privilege of associating with many of the basic and clinical neurological scientists in this country, and since early of the 50s I have had the great advantage of serving on several of the advisory groups of the National Institutes of Health.

The past 35 years have been ones of enormous progress in medicine, times that have made it a joy to be alive and to participate. To a considerable degree this growth of medical knowledge and the improved health of America that has accompanied it has been the direct result of the Congressional wisdom that created the National Institutes of Health and allowed them to flourish. But there is a dark side to our progress in medicine. As we have conquered other diseases and life has lengthened not only for Americans but for countless others in this world, late life neurological disorders have increased greatly so as to nibble away at what would have been the best years for many of the survivors. Stated succinctly, as a person I hugely admire Senator Javits' determined fight in meeting the awful limitations of amyotrophic lateral sclerosis, but as a physician and scientist I feel humiliated that we have no way to prevent or specifically treat his illness. But the promise is in sight, and in that direction we need your assistance.

Let me touch first on a human dimension. One of the major damaging effects of neurological disease is that it lies on the body's outside. One can hide beneath the surface heart trouble, an ulcer, or even cancer but one cannot keep from others the fact that one is unable to walk properly, speak regularly, that one twitches or shakes or, worst of all, forgets or cannot understand. Disease of the brain or nerves strikes at the essence of our humanness and in so doing sets the victim apart. Part of the dread of developing multiple sclerosis or parkinsonism or Alzheimer's Disease is that the illness not only will bring incapacity but that all the world can immediately witness our incapacity. For many neurological victims this knowledge brings not only embarrassment but even shame. They need our help.

Presently, the major neurological problems demanding solution lie in the area of so-called degenerative neurological diseases. Alzheimer's disease, stroke, parkinsonism, multiple sclerosis, the epilepsies, brain and spinal tumors, the motor diseases, including Huntington's and amyotrophic lateral sclerosis, and the muscular dystrophies affect well over 10% of our population. Most but not all of these illnesses strike in the later years of life. But in whatever age group, the majority eventually produce a state of total disability which can last for several years. Many affect the victim's mind as well as his mobility. Shamefully for us neurologists and scientists in none of these disorders do we have satisfactory knowledge of their specific cause or of an effective clinical prevention or treatment. To put things in perspective: Alzheimer's disease alone incapacitates some 5% of all persons over age 65 and a chilling 20% of those who reach 80 years, an age which already approximates the life span of half the women in this country. In 1980, the cost of care for this single disorder approached six times the total United States health research budget. Furthermore, present population trends suggest that unless we find solutions by the year 2000, the ratio of treatment costs to total research expenditures will reach 16:1: literally a pound of treatment for one disease for an ounce of prevention for all diseases.

But all is not gloomy--there is hope and recent research already has lead to some progress. Parkinsonism can be ameliorated at least transiently with L-dopa. Patient care in epilepsy has greatly improved thanks to new anticonvulsants and better general measures. Mortality in stroke has declined substantially, perhaps because of better prevention. Many birth defects and early life diseases can now be prevented by genetic recognition and wise counselling. New and improved chemotherapy has benefitted patients with diseases as different as brain tumors and myasthenia gravis.

Even more important than the above successes, however, is the fact that we stand at the threshold of a much stronger understanding of our brains and, therefore, of ourselves and our sometimes irrational behavior. Furthermore, the experimental techniques that have been developed to learn more about fundamental neuroscience are beginning to unravel the secrets of dread neurological diseases. Powerful new research methods abound: scientists now are able easily to grow the cells of brain and nerves in cultures where their individual susceptibilities to disease or treatment can be examined specifically. By combining techniques of immunology and genetics one can identify singular chemical qualities of nerve cells in different parts of the nervous system so as to pursue how disease selectively identifies its neuronal victims. Entire new families of chemical messengers have been found in the brain, bringing hope that they carry a key to hitherto mysterious illnesses where replacement therapy may bring future prevention or cure. Our papers already have carried the news that the application of recombinant DNA techniques has identified the locus of the abnormal genes in muscular dystrophy and Huntington's disease. This is but a first step that undoubtedly will be repeated in understanding a whole series of neurological disorders, including Alzheimer's disease, which show a hereditary predisposition. Even the problem of stimulating regeneration in the central nervous system no longer looks hopeless. Ingenious experiments have shown that interrupted central nervous system fibers can be retracked by enclosing them in peripheral nerve sheaths. It has been proved possible to grow transplanted nervous tissue in the brains of mature experimental animals. Such experiments give hope that some of the previously devastating effects of stroke, head trauma and paraplegia may in the near future be improved or reversed.

Fortunately not only is the time ripe for great breakthroughs in understanding the brain and treating its diseases but gifted young people are becoming increasingly available to do the job. Brain science, neurobiology, has been the fastest growing field among young persons entering bioscience for the past 10 years. As a result, we are blessed with an abundance of strongly motivated, well educated, and highly intelligent young scientists and scientific physicians whose life ambition is to unlock the secrets of the brain and to conquer its diseases. However fine their motives they can create no discoveries without the space, equipment, and salaries to do the job.

Last year, thanks to the effective efforts of your committee and that of the House of Representatives, the Congress increased the budget of NINCDS, the chief institute involved in brain research, by 10%. I respect~~ively~~fully urge you to continue the pattern of such increments for at least the next two years in order to assure a true growth and stability in the numbers and quality of those who address their lives to brain research. It takes time to recruit, equip, and launch a scientist. Because of the nature of our federal system, a single year's increased appropriation can affect only grant applications already received by NIH. Nevertheless, by your wise decisions of last year, high quality grant applications have now increased for 1985 and a similar upward trend can be expected for 1986 and 1987. I plead with you to take advantage of the opportunity.

In summary, the human need is great, the opportunity for neurological discovery is immense, and high quality clinical and basic neuroscientists are available. I greatly hope that the Congress will strengthen the promise it gave last year to the American people and will repeat for fiscal year 1985 the beneficial incremental appropriations granted to NINCDS in 1984.

Biography of Dr. Fred Plum

Mailing Address:	Professor and Chairman Department of Neurology New York Hospital-Cornell Medical Center 525 East 68th Street New York, New York 10021 Tel.: 212-472-5744 S.S.#: 137-14-6284
Born:	January 10, 1924, Atlantic City, New Jersey
Premedical Training:	Dartmouth College, Hanover, New Hampshire 1941-1944, B.A.
Medical Training:	Dartmouth Medical School, 1944-45 Cornell University Medical College, M.D., 1947
Internship, Residency and Fellowship:	Intern, Medicine, New York Hospital, N.Y., 1947-48 Assistant Resident, Medicine and Neurology, New York Hospital, N.Y., 1948-50 Fellow, Neurology, 2nd (Cornell) Neurological Division, Bellevue Hospital, 1950-51
Professional Experience:	Physician to Outpatients, New York Hospital, 1950-51 Instructor, Medicine (Neurology), Cornell University Medical College, 1950-53 Head, Neurology Section, U.S. Naval Hospital, St. Albans, N.Y., 1951-53 Assistant Professor, Associate Professor and Professor, Medicine (Neurology), University of Washington, School of Medicine, Seattle, Washington, 1953-63 Anne Parrish Titzell Professor and Chairman, Department of Neurology, Cornell University Medical College, and Neurologist-in-Chief, New York Hospital, 1963-present Visiting Scientist, Brain Research Laboratory, University of Lund, Sweden, 1970-71
Boards:	Certified, American Board of Psychiatry and Neurology, 1956
Honorary and Professional Societies:	Alpha Omega Alpha (Cornell), 1947 American Neurological Association, (Council 1961-63), Vice President, 1974, President, 1976-77 American Academy of Neurology, (Council 1961-63) International Society for Neurochemistry American Epilepsy Society American Society for Clinical Investigation, Emeritus Association for Research in Nervous and Mental Diseases, President, 1973 Trustee, 1964-- Society for Neuroscience Harvey Society of New York, President, 1977-78 Association of American Physicians New York Neurological Society, President, 1969-70 Societé Francais de Neurologie, Honorary Societa Italiana di Neurologia, Corresponding Canadian Neurological Association, Honorary Association of British Neurologists, Honorary, Society for Neuroscience Neuroscience Research Program, Associate, Boston and New York, 1977- Neurosciences Institute, Rockefeller University, 1982- Corresponding Member, Swiss Neurologic Society, 1983-

Activities:

Training Grant Committee, NINCDS, NIH, 1959-63, 1971-73
Study Section, NINCDS, NIH, 1964-68
National Advisory Council, NINCDS, NIH, 1977-81
Editorial Board, Archives of Neurology, 1955-59
Chief Editor, Archives of Neurology, 1971-76
Editor-in-Chief, Contemporary Neurology Series, F.A. Davis Company, Philadelphia, Pennsylvania, 1966-
Editor, Annals of Neurology, 1976-
Chairman, Ad Hoc Committee on Electrosleep and Electroanesthesia, National Research Council, 1974
Consultant to the McKnight Foundation, Minneapolis, MN, leading to the initiation of the McKnight Foundation Fellowship and Research Programs in Neuroscience, 1976-
Chairman, Fellowship Committee, McKnight Foundation, 1976-
Board of Visitors for the Arts, University of Puget Sound, 1979-
Board of Overseers, Cornell University Medical College, 1980-1981
Fellowship Awards Committee, Esther and Joseph Klingenstein Fund, Inc., 1981-
Scientific Review Committee for the Neurosciences, Weizmann Institute, Rehovot, Israel, April, 1983.

Honors:

Doctorate in Medicine, honoris causa, Karolinska Institute, Stockholm, May, 1982
Alumnus of the Year Award, Cornell University Medical College, 1983

Honorary Lectures:

Brown Lecture, UCLA Medical School, 1970
Dedication Address, opening ceremonies of the University Hospital, University of Western Ontario, September, 1972
Farquharson Memorial Lectures, University of Toronto, February, 1973
Stephens Visiting Professor, University of Colorado, Denver, Colorado, March, 1973
Baldwin Memorial Lecture, Queen's University, Kingston, Ontario, March, 1974
Rogowski Memorial Lecture, Yale School of Medicine, March, 1974
Alpers Lecture, Jefferson Medical College of Thomas Jefferson University, March, 1975
AOA Lecture, Emory University School of Medicine, April, 1975
Pahlavi Lecture Series, Shiraz and Tehran, Iran, June, 1975
Aird Visiting Professor of Neurology, UC at San Francisco, October, 1976
Gitt Visiting Professor, Washington University, St. Louis, February, 1977
Matas Lecture, Tulane University School of Medicine, April, 1977
AOA Professor, University of Washington School of Medicine, 1978
Merlis Lecturer, University of Maryland, 1980
AOA Lectures, University of Western Ontario, 1981
Nobel Foundation Lecture: "Outcome from Medical Coma", Karolinska Inst., Stockholm, December, 1981
McDonald Lecture, Ontario Heart Association, London, Ontario, 1982
The Wartenberg Lecture, American Academy of Neurology, April, 1982
Australian Neurological Association Lecture, 1983
Leaky Foundation Lectures, Pasadena, January, 1984
Rogers Memorial Lecture, Milwaukee Academy of Medicine, February, 1984
Senatorial Lecturer, Loyola-Stritch School of Medicine, Chicago, March, 1984

Senator WEICKER. We have, as you can see, witnesses galore, and I would very much like to have you summarize your thoughts as they relate to your testimony and what we have heard from Senator Javits.

Dr. PLUM. Thank you. Senator Specter, Senator Proxmire.

If ever there was an anticlimax, this is it. I think it is fair to say to start that, as the Senator indicated, he stands as an inspiration to all of us. I think our admiration is also tinged with our shame.

I think that until the past few years we haven't had sense of any direction of how we can touch disorders such as that which Senator Javits has, disorders of the motor system.

I think even more important perhaps, from the standpoint of the long-range perspective of this committee in the future, is that as life has lengthened, due in very considerable effect from the wise actions of the Congress and the National Institutes of Health and the effect that they have had on health and medicine in the world, increasing numbers of persons, as they have reached the golden years, have suffered what Senator Javits calls the condition of the living dead, patients with neurological disease, wear their disabilities on the outside.

One can hide a heart attack, one can hide cancer, but when one is crippled, can't speak clearly, especially when one can't remember well or when one is confused, this is there for all the world to see. People are profoundly embarrassed, and some are, in fact, ashamed for these disabilities. At the present time, as I am sure the Senators know, roughly 6 to 7 percent of the population of the United States over the age of 65 is incapacitated by degeneration of the brain by the disorder called Alzheimer's disease. That number approaches something in the neighborhood of 18 to 20 percent by the time individuals reach the late seventies or early eighties. Half the women in America at the present time are living to almost that age, where they are threatened with a 1 out of 5 chance of losing sufficient mental capacity so they cannot function normally.

I recently calculated the cost of such a staggering impact on the people. Our annual expenditure at the present time is roughly equal to about five times the total national expenditure for health research, the total, of just one disease.

If the population trend continues until the year 2000 as it has been for the past several years—and there is no reason to think that it won't—we can anticipate that we will be spending 16 times the total health research budget on the care of patients incapacitated by Alzheimer's disease alone.

That is essentially—to compound an old fable, that is a pound of treatment for one disease for an ounce of prevention for all diseases, and simply in terms of economic standards that really doesn't make common sense. Never mind the human tragedy, which is an even more tragic dimension.

As the Senator indicated, thanks to the extraordinary explosion of new techniques, new understanding in neurobiology in the last decade, we genuinely stand on the threshold of years of understanding for the first time in human history how the human brain works, how, at least to some degree, emotions govern behavior, how in some ways our irrationality within a 21st century governed by libraries and computers is generated from instincts that were born 100,000 to 200,000 years ago.

We stand, as you well know from the public press, for the first time having bracketed the genes that are responsible for Huntington's disease and some of the muscular dystrophies.

Most of the degenerative diseases of the nervous system have a hereditary component to them. Similar investigations in the future, coupled with precise immunologic pinpoints on the cells themselves, will, we believe, lead us to the molecular understanding of cellular diseases such as amyotrophic lateral sclerosis. So the need is there, the initial tools are there, and the most important thing perhaps is over the past 5 years brain science neurobiology has become the single area with the largest number of best graduate students, and young physicians, scientists have turned their attention in terms of treating these mutilations of humanity.

So that I would in the first position, appreciate enormously the Senator's plea for increased support of the national communicable disease's work on disorders and reiterate his plea that not only is the need great and the scientific time ready, but the opportunity stands abundantly available for your wise support.

As a final comment—and you all know this as well as I—one of the realities of the Federal system is that money appropriated in any given year, except for the present fiscal year, must deal with grant submissions already in the register.

If one expects to take advantage of the chemotoxic effect of the dollar, which is to bring more scientists in the field of brain research of dread brain diseases, one must continue to strengthen the funding which makes that possible, and I would in that sense then strongly share the Senator's plea for increased funding in 1985.

Thank you very much.

Senator WEICKER. Thank you very much, Dr. Plum. I appreciate your testimony.

Jack, you are not only a man of great wisdom but great courage and great foresight. You have always anticipated our Nation's problems long ahead of the Congress, and the safeguards that you have put in for us, in every sense of the word have been very much needed, and I can assure you that your words here will have quite an effect on the budget.

More importantly, as Bill said, it is great to see an old friend. I will say this also. As was mentioned by Bill and others, nobody should have any sympathy for this man. He is just as hard on all of us as he ever was.

Jack, thank you very much.

Senator JAVITS. May I for the record state that the curriculum vitae of Dr. Plum is backing for his authoritative statements, and I would like to thank him very much.

Thank you, Mr. Chairman, Senator Proxmire.

Senator WEICKER. Thank you.

Now, we have a lot of ground to cover, and I want to make sure that everybody has the opportunity to testify. So we will be using the system which we have used throughout all the public hearings, having the 5-minute clock in front of us. We will start with the green light, and you will have 4 minutes to summarize, and you will see a warning yellow light, and then finally when the red light comes on hopefully the witnesses will go ahead and terminate their testimony.

I might add that I find your testimony absolutely fascinating, of all those that are in this room and all those that have proceeded to come. I could spend all day. Unfortunately, as a matter of courtesy to all the witnesses, not to the chair but to your fellow witnesses, I would appreciate it if those of you who are going to testify would stay within the bounds of 5 minutes.

STATEMENT OF DR. ROBERT J. RUBEN, CHAIRMAN, DEPARTMENT OF OTOLARYNGOLOGY, ALBERT EINSTEIN COLLEGE OF MEDICINE

Senator WEICKER. Our first witness is Dr. Robert Ruben, chairman of the Department of Otolaryngology——

Dr. RUBEN. Ear, nose, and throat.

Senator WEICKER. Otolaryngology——

When I took over the chairmanship of the hearings, I told them I chair most of the hearings in person, and it is going to take me about 3 years to get all this. This is part of the learning process. I will be able to astound all of my friends in Washington, DC, with my medical knowledge.

Of the Albert Einstein College of Medicine.

PREPARED STATEMENT

It's nice to have you, and you may proceed, but first we will enter your statement in the record.

[The statement follows:]

STATEMENT OF DR. ROBERT J. RUBEN

Mr. Chairman, I am Robert J. Ruben, M.D., Chairman of NCR. I am pleased to appear before you today and to add my gratitude for the support that the Committee has shown for the work of NINCDS.

My testimony today will focus on two areas: the volume of extraordinarily meritorious scientific grants applications awaiting funding and the research apportunities those applications represent.

The Performance of NINCDS. Applications for NIH grants go first to the NIH Division of Research Grants where they are numbered and assigned to the appropriate Institute and to a Scientific Advisory Group for review of their scientific and technical merit. The study section assigns a priority rating to each proposal based on a scale of from 100 to 500 with 100 being a perfect score. Once reviewed for merit, applications assigned to the Institute are referred along with recommendations of the merit review group to the National Advisory Neurological and Communicative Disorders and Stroke Council. The National Advisory Council then reviews the scientific merit recommendation of the applications and judges the significance of applications to the Institute program and objectives. NINCDS may award grants only if recommended favorable by is Council.

The total numbers of applications received by the Institute has increased dramatically as the table below shows.

Table 1

Number of Applications Received

1978	1,271
1979	1,236
1980	1,262
1981	1,547
1982	1,717
1983	1,843

The rate of application in 1984 to date indicates that they will probably exceed 2,000.

The initial review of scientific and technical merit and the second review of merit and significance to the Institute's programs and objectives constitute a dual review process of grant applications. An important indicator of the quality of scientific proposals, then, is the score at which programs are funded. This is sometimes referred to as tho pay line. The closer the pay line is to 100, the greater scientific merit the proposals have. As Table 2 indicates, the pay line for the National Institute of Neurological and Communicative Disorders and Stroke has improved dramatically and is comparable to other Institutes within NIH.

Table 2

Pay Line for Applications

	NINCDS	NCI	NHLBI	NIADDKD
1980	232	218	206	221
1981	206	197	208	202
1982	189	183	196	180
1983	185	181	195	184

Most individuals familiar with the NIH scientific review process would have to agree, that scores of 220 to 180 indicate very, very good applications of high scientific merit. It is this group of promising scientific research which is not receiving adequate funding.

The NIH, under agreements worked out several years ago, will award 5,000 competing projects in 1984. The NINCDS share of the 5,000 is 524 competing projects. This, however, is an extremely minimal number. The NINCDS should be funding at least 700 competing projects. It is important to note that since 1978 the number of applications to the NINCDS has increased 37%. Perhaps of even greater significance is the fact that the priority score has increased by a factor of 20%. That is to say, the average lower priority score is 20% lower than it was in 1980 (the lower the score the greater the scientific merit as determined by an independent panel of experts). Thus, we see clear, quantitative evidence of increased number of grants and increased quality in these grants. Most of these high quality grants, under present budget, cannot be funded.

Targets of Research Opportunity. Research opportunities are now available to address the problems of brain and communication. Congressional attention to the programs of the NINCDS, at this time, will clearly provide for similar excellent opportunities for the prevention of the disorders of the brain as has occurred in the prevention of heart disease.

The key- to the basic understanding of how the brain works, including memory, learning, and control of bodily functions, are now available.

Stroke remains the third leading cause of dealth and the second leading cause of long-term disability in the United States. The means for stroke prevention and protecting the brain during a stroke are being developed and must be continued and accelerated.

Dementia or senility has been demonstrated by the NINCDS researchers to be a disease of a specific focal area of the brain. Early experiments in preventing and arresting this disease are just beginning and must be expanded. Getting old does not necessarily mean that one becomes senile; there are ways of preventing it. But prevention requires the resources to further explore the scientific information which we already have.

Head and spinal cord injuries are the principal causes of dealt in accidents. Accident is the fourth leading cause of death in the United States; the largest cause of death for young Americans. The NINCDS program of Health and Spinal cord Injury Research centers must be enlarged if we are to prevent death, paraplegia, epilepsy or the loss of mental function due to these injuries which occur so frequently in our young population. Again, our only obstacle is the amount of money which we have to fund these activities.

Developmental disorders such as cerebral palsy, genetic birth defects of the brain and spinal cord, take horrible toll and should be preventable. In some of these developmental disorders, the NINCDS scientists have already shown that enzyme replacement therapy in early life provides for prevention of deterioration of the nervous system. One does not have to detail the cost of human suffering, in wasted lives, and the tremendous cost of institutionalizing many of these individuals for their entire lifetime. These costs, both the measurable and immeasurable, can be saved by only a relatively modest increase in funding for the programs in the NINCDS.

Of the 600 diseases affecting the brain and the nervous system, many affect relatively small numbers of Americans. If we are to achieve the goals Congress set out in the recently enacted Orphan Drug Act, the NINCDS must be given the opportunity to develop new drugs needed and to undertake the clincal testing required. This will require $4 million ($2.5 million for drug development and $1.5 million for clinical testing). This money is not available in the present budget.

Prevention is the main thrust of the NINCDS research program in order to diminish loss of brain function. However, central nervous system regeneration research is moving ahead steadily and if accelerated could be the means of restoring lost function following a stroke, head and spinal cord injury, mutiple sclerosis, amyotrophic lateral sclerosis (ALS or Lou Gehrig's Disease), Parkinson's Disease and Huntington's Disease. Again, the major obstacle is not the lack of scientists, not the lack of the fundamental discoveries, not the lack of ideas, but the lack of money in order to implement the needed research.

The research opportunities available should be thought of not as just the development of a single drug or specific breakthrough, although such advances do occur. The opportunities before us encompass revolutionary advances in technology and the creation of entirely new disciplines.

For example, technology has now brought us the position emission tomography (PET) scanner and the nuclear magnetic resonance (NMR) which provide a window on the chemical interactions which accompany perceptions, memory and motor movements.

The fields of immunclogy and biochemical genetics were unheard of not so many years ago. Now they are producing monoclonal antibodies and genetic probes to investigate the molecular machinery of neural cell functions.

Appendix

NCR Budget request for NINCDS for FY 85

1. Research Grants	$398,028
A. Research Projects	41,557
B. Research Center	37,096
Subtotal	476,681
2. Training Programs	12,703
3. Research & Development Contracts	24,033
4. Intramural Research	33,637
5. NIH Services	18,945
6. NINCDS Program Direction	13,463
Total	$579,462

Dr. RUBEN. Thank you very much.

My capacity here today is really as chairman of the National Committee for Research in Neurological and Communicative Disorders, and it is very hard to follow both Senator Javits and my colleague from New York, Dr. Plum, and I would like to use this time to further emphasize and perhaps detail some of the things that Senator Javits and Dr. Plum had brought up.

First of all, I think both Senator Javits and Dr. Plum have made very aware that we now have the possibility in neurological diseases, brain diseases, and other disorders of those who can't hear and those who can't speak of making substantive breakthroughs, where we are now able to make people's lives better. We are able to make the crippled walk, the deaf hear, and the dumb speak.

The thing that is holding us back essentially is resources, equated with people and money. Dr. Plum emphasized that the people are ready. We have a visible evidence that the people are ready by looking at the very high priority scores that grants have gotten within the NINCDS.

We have seen through the Congress last year of the increased appropriation. Rather dramatic things have happened. Two or three things that really stand out are:

One, the discovery of the basic genetics which will lead to Huntington's disease.

The second is the use of neurotransplants, and the third is the biochemical determination of how the ear grows.

These are three amongst many, many things. These are the types of things which will enable us to apply this to the human condition. These are the types of things that will be able to prevent the types of disease that Senator Javits has had, and for many others this will be the type of thing that will be able to prevent the hearing loss in the elderly, that will be able to prevent Alzheimer's disease.

There is only one thing that is stopping us—money. How slow do you want us to go?

When I say us, I mean the whole community of neuroscientists, physicians, people who understand and care for these things.

This is an extremely exciting and revolutionary time within neurosciences and communicative disorders. The appropriations which have been requested by two independent groups, the Treco-Kitt report, which was requested by the Senate, which the Senator had referred to, and also the NCR's own policy committee, has arrived at a figure of $579 million. This has been calculated as being able to take care of those grants, those centers, which now are able to be utilized for work in this area.

This is a substantive amount of resources. However, it gets nowhere near the moneys that have already been appropriated for cancer and heart.

In this area the Congress has seen the tangible results of its allocation of resources, the tangible results of individuals living longer and more productive. You are victims, really, of your own success because now we have people living longer and they are affected with various neurological and degenerative disorders which makes life at best empty and at worst something which we really don't prefer to mention.

It is now the time, there is now the opportunity for this committee to increase the resources, to increase the funding so that we may be able to take this extension of life and make it useful to the person, make it useful to the society.

This is one end of the spectrum. The other end of the spectrum are the children and the infants. The same application can be applied to those children who were born with congenital malformations, congenital diseases, of which most are genetic, to the hearing impaired, to many of the retarded, and to many, many other conditions. It is really almost an engineering feat.

How slow do you want us to build this bridge? How slow do you want us to build this highway?

We as a community can build it. It is up to you to decide the pace at which you are to build it.

Thank you very much.

Senator WEICKER. Thank you very much, Dr. Ruben. Thank you very much.

STATEMENT OF J. ALFRED RIDER, M.D., PH.D., PRESIDENT CHILDREN'S BRAIN DISEASES FOUNDATION

PREPARED STATEMENT

Senator WEICKER. The next witness is Dr. Alfred Rider, president of the Children's Brain Diseases Foundation.

We will insert your prepared statement in the record and then you may proceed.

[The statement follows:]

Statement of J. Alfred Rider

Summary of Recommendations

Batten's disease is a neurological disorder which may have an incidence as high as 1 in 12,500 births, similar to other common genetic disorders. It manifests itself in previously normal children at the approximate ages of 4 to 8 and is characterized by a slow progression of clumsiness, stumbling failure of vision, seizures, changes in personality and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or early twenties. The cost of taking care of one of these children through their lifetime may run well over one million dollars. The changes which occur in the brain in these children are quite similar to many of the changes in the aging person. Thus, effective treatment for Batten's disease may also allow us to alter the aging process of senility in all humans.

Batten's disease is the only neurological disorder for which animal models are available (dogs and sheep) to perfect diagnostic tests and to develop treatment to better elucidate the pathophysiology of the disease, assist with genetic counseling and evaluate therapy. Additional funds are necessary to further the research in this important disease. Since the basic cause of the disease is probably due to a defect in the peroxidase enzyme system in the brain, research is being directed toward penetration of the blood brain barrier to peroxidase. Further research is being directed toward drugs which may block the production of the accumulated peroxidase or lipoxygenase.

Recommendations to insure continued support:

(1) That wording be re-installed similar to that used in previous Senate Committee Reports namely; "The Committee... expects the Institute to expand its research on Batten's disease and related areas within the limits of high quality research available.", be used in your report for fiscal year 1985.

(2) In your appropriations to the N. I. H., we recommend that a specific line item be included suggesting the sum of $700,000 be made available for fiscal year 1985 for research on Batten's disease.

Statement

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to testify before the Senate Appropriations Subcommittee on Labor-Health and Human Services, Education and Related Agencies and support the budget requests of the National Institute of Neurological and Communicative Disorders and Stroke.

Batten's disease is a neurological disorder which manifests itself in previously normal children at the approximate age of 4 to 8 and is characterized by a slow progression of clumsiness, stumbling, failure of vision, seizures, changes in personality and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or early twenties.

One of the most promising theories about the disease has resulted from the discovery of an abnormality in the peroxidase enzyme system in the brains of children with Batten's disease. This results in an accumulation of a yellow pigment, ceroid lipofuscin, in the brain cells producing slow destruction and progressive deterioration. These changes are quite similar to the changes that take place in all brains as they age. Thus, effective treatment for Batten's disease might delay the normal aging process.

Considerable effort in the last year has been directed toward improving upon a blood chemistry test to identify children with the disease and their carriers. Additional studies have been done on the Kopang dogs which have a disease similar to Batten's disease in humans. For example, several defective puppies have been injected intra-arterially with crystaline peroxidase. These studies have shown that the blood brain barrier can be penetrated. Of course, much additional work must be done before this technique may be utilized for humans.

Thus, we must continue to make funds available to continue with this vital research to better elucidate the pathophysiology of the disease, assist with genetic counseling, and initiate and evaluate therapy such as, feeding or injecting peroxidase and/or various anti-oxidants. It has been found, for example, that horseradish and avacado are high in peroxidase. It is possible that pure enzyme may be obtained from the placenta or from DNA altered bacteria.

Research is the only way to solve this disease and prevent the devastating tragedy in families who have children so afflicted and effect tremendous savings to society as a whole. The cost of care for each child is enormous and may be as high as $50,000 to $100,000 a year. Thus, 10 children such as these would cost more per year than the funds we are requesting.

Finally, the possible spin off of enabling us to alter the aging process of senility in all humans makes the value of this research unlimited.

In the last year, research has expanded and is progressing rapidly. This momentum must be maintained. For example, we are in the process of assisting with the development of two Batten disease centers, one at the University of Indiana and one at the University of Florida. Because of the constraint on time, I cannot review the research studies underway but I have enclosed them in the prepared addendum. Suffice it to say that there are over thirty four principal investigators from major universities, medical centers and institutes throughout the world involved in various phases of research pertaining to Batten's disease. If funding is provided, the chances of the development of a specific treatment program in the forseeable future appear to be very good.

We were, however, extremely disappointed that last year the Appropriations Committee made no mention of Batten's disease although in the appropriation bill for 1981-82, the wording was as follows: "The Committee...expects the Institute to expand its research on Batten's disease and related areas within the limits of high quality research available." We feel it is extremely important for the N. I. H. to have some strong direction into the type of research it supports. Thus, it is fitting that the final appropriations bill contain wording identical or similar to that quoted above.

For fiscal year 1983, there were only two grants from the N. I. H. which specifically related to Batten's disease. One for $91,262, and the other was for $59,628. Incidentally, the latter was not for a study in the United States. We do not believe that the National Institute of Neurological and Communicative Disorders and Stroke should be so independent and so hallowed that direction cannot be given to them with respect to encouraging and sponsoring research on Batten's disease. It is discouraging and counter productive to have our researchers apply for federal grants on Batten's disease and be turned down time and time again for lack of funds. Thus, it is our firm recommendation that you provide a line item request, that at least $700,000 be used for research on Batten's disease for fiscal year 1985.

This is the bare minimum in order to keep research progressing in this important field.

ADDENDUM

Scientists Actively Working in Research on Batten's disease

1. Doctor Donald Armstrong
   University of Florida, Department of Opthamology
   Relationships of Peroxidase to Batten's disease
   Canine Retinal Degeneration: An Approach to Therapy
   Peroxidase Deficiency & Peroxidase Regulating Enzymes
   Peroxidase Activity in Human and Canine Ceroidlipofuscinosis, with Special Emphasis on the Eye

2. Doctor Robert J. Baumann
   Department of Neurology
   University of Kentucky & Section on Epidemiology OBE,
   Office of the Director, N.I.N.C.D.S., Bethesda, Maryland
   Leukocyte Ultrastructure

3. Doctor Milton Brightman
   Lab. of Neuropathology & Neuroanatomical Sciences
   N. I. N.C.S. & National Institutes of Public Health/
   Department of Health and Human Services
   Transport of Horseradish Peroxidase Across Blood Brain Barrier

4. Doctor Glyn Dawson
   Associate Professor, Depts. of Pediatrics and Biochemistry
   The University of Chicago
   Pre-Natal Diagnosis and Enzyme Replacement Therapy Approaches to the Detection of Neuronal Ceroid Lipofuscinosis in Cultured Skin Fibroblasts

5. Doctor T. L. Dormandy
   Whittington Hospital, London
   Free Radicals and Lipopigments

6. Doctor Edward Dratz
   Associate Professor of Chemistry & Biochemistry
   University of California, Santa Cruz
   Measurement of Fluorescent Lipopigment, Peroxidized Fatty Acids, Vitamin E, Effects of Antioxidants on Lipopigment Formation

7. Doctor Paul Glees
   University of Cambridge, Anatomy School, Cambridge
   Electron Microscopic Studies on Neural Lipofuscin: Accumulation and Removal
   The effects of Centrophenoxine in the Central Nervous System

8. Doctor H. H. Goebel
   Division of Neuropathology, University of Gottingen
   The Ultrastructural Spectrum and Diversity of Lipopigments in the Neuronal Ceroid-Lipofuscinosis

9. Doctor John M. C. Gutteridge
   Division of Antibiotics, National Institute for Biological Standards and Control, Holly Hill, Hampstead, London
   Fluorescent Products of Phospholipid Peroxidation: Formation and Inhibition in Model Systems

10. Doctor Egill Hansen
    Department of Opthalmology, Rikshopitalet, The National Hospital, University of Oslo, Norway
    The Significance of Psychophysical and Electrophysical Methods in the Diagnosis of Juvenile Neuronal Ceroid-Lipofuscinosis

11. Doctor Ann Harden
    Department of Clinical Neurophysiology, The Hospital for Sick Children, London
    Neurophysiological Studies in Children With so-called Neuronal Ceroid Lipofuscinosis

12. Doctor Denham Harman
    The University of Nebraska Medical Center
    Brain Lipid Composition

13. Doctor K. U. Ingold
    Associate Director, National Research Council of Canada
    Division of Chemistry
    Resistance to Oxidation and the Natural Antioxidant Levels in Membranes from Human Cells

14. Doctor Gunde Egeskov Jensen
    The Laboratory of Biochemistry and Toxicology, The Institute of Biology and Chemistry, University of Roskilde, Denmark
    Glutathione Peroxidase Activity in Leucocytes, Erythrocytes and Serum from Juvenile Form of Neuronal Ceroid Lipofuscinosis

15. Doctor R. D. Jolly
Department of Veterinary Pathology and Public Health, Massey University, Palmerston North, New Zealand
Ceroid-Lipofuscinosis: The Ovine Model

16. Doctor Edwin Kolodny
Associate Director, Eunice Kennedy Shriver Center for Mental Retardation, Inc., Waltham, Massachusetts
Pathogensis of the Neuronal Ceroid-Lipofuscinosis

17. Doctor Nils Koppang
Veterinaerinstuttet, Oslo, Norway
Histochemical Evidence of Lipid Peroxidation in Canine Ceroid Lipofuscinosis

18. Doctor Martin M. Maltempo
Assistant Professor of Physics, University of Colorado Medical Center
Monitoring of Peroxidase and Free Radicals in Canine Retinal Tissue Subject to a Degenerative Disease in Which There is an Accumulation of Pathologic Lipopigments of the Ceroid Type: A Model for Batten's disease

19. Doctor Jaime Miquel
NASA, Ames Research Center, Moffett Field, CA
Analysis of Pigment Lipofuscin

20. Doctor Erling Gronvold Olsen
University Eye Department,Rikshospitalet, University of Oslo, Norway
Fluorescein Angiography in Ceroid Lipofuscinosis

21. Doctor Vimal Patel
Assistant Professor of Pathology
Indiana University School of Medicine
Antioxidant Treatment of Batten's Disease

22. Doctor Alan K. Percy
Associate Dean, Office of Research, Charles R. Drew Postgraduate Medical School, Los Angeles
Salutory Effect of Selenium, Erythrocyte Glutathione Peroxidase

23. Doctor Michel Philippart
Neuropsychiatric Institute, University of California, Los Angeles
Treatment of Batten's disease with Antioxidants

24. Doctor Mark Poznansky
Associate Professor of Pathology, University of Alberta
Enzyme Replacement and Enzyme Engineering

25. Doctor Raju Pullarkat
New York State Institute for Basic Research in Mental Retardation
Lipopigments in Aging and in Ceroid-Lipofuscinosis
Docosahexaenoic Acid Levels in Brains of Various Forms of Ceroid-Lipofuscinosis

26. Doctor Julius Schultz
Director, Pananicolaou Cancer Research Institute
Miami, Florida
Discovery and Characteristics of Leukocyte Peroxidase and the Purification and Administration to Animals

27. Doctor Gunther Schwendemann
Division of Neuropathology, University Hospital, Eppendorf, Hamburg
Diagnosis of Juvenile Ceroid-Lipofuscinosis by Electron Microscopy of Lymphocytes and of Rectal, Skin and Sural Nerve Biopsy Tissue

28. Doctor Aristotle Siakotos
Professor of Pathology, Indiana University Medical Center
Development of a Reliable Blood Test for Batten's disease
Recent Developments in the Isolation and Properties of Autofluorescent Lipopigments

29. Doctor P. E. Spoerri
Department of Histology and Neuroanatomy, University of Gottingen, Gottingen
Ultrastructural Age Changes in Neurons and Myocardium in Culture. The effects of Centrophenoxine on Age Pigment.

30. Doctor Satish Srivastava
Department of Human Biological Chemistry & Genetics
The University of Texas Medical Branch
Purification and Properties of Leukocyte Peroxidase
Biochemical Studies in Neuronal Ceroid-Lipofuscinosis

31. Doctor Al Tappel
Division of Food Science & Technology, University of California, Davis
Properties and Functions of Flutathione Peroxidase and Pentane Analysis of Lipid Peroxidation Damage to Quantitate Effects in Nutrition

32. Doctor T. Westermarck
Rinnekoti Institution for the Mentally Retarded, Espoo,
Institute of Radiation Protection, Helsinki, Finland
Sodium Selenite Absorption and Losses in Spielmeyer-Sjogren Type of Neuronal Ceroid Lipofuscinosis (Batten's disease) Using Total Body Counting for ^{75}Se Detection
Studies on the Effects of Selenium Administration to Neuronal Ceroid Lipofuscinosis Patients with Special Reference to Reduced Glutathione

33. Doctor John R. Wherrett
Professor of Neurology Program, University of Toronto
Isolation of Fluorescent Material in the Juvenile Form of Batten's disease

34. Doctor Leon Wolfe
Hopital Neurologique de Montreal, Montreal Neurological Hospital, Canada
Characterization of the Accumulated Retinol Compounds in Batten's disease
An Analysis of Urine Sediment in Subjects with Batten's disease

35. Doctor R. D. Jolly
Massey University, Palmerston, New Zealand.
Studies on mannosidosis and ceroid-lipofuscinosis in cattle, sheep and dogs.

36. Doctor Satish K. Srivastava
University of Texas Medical Branch, Galveston
Biochemical studies in neuronal ceroid-lipofuscinosis in humans and mice.

Dr. RIDER. I am Dr. J. Alfred Rider, president of the Children's Brain Diseases Foundation.

The children's brain diseases has decided to concentrate on a disease called Batten's disease. We felt that was a prototype of any brain disease that affects children.

Batten's disease is a neurological disorder which manifests itself in previously normal children at the approximate ages of 4 to 8 and is characterized by a slow progression of clumsiness, stumbling, failure of vision, seizures, changes in personality, and dropping of scholastic grades. The disease eventually leaves them totally disabled and unable to care for themselves and usually ends in death in the late teens or early twenties.

One of the most promising theories about the disease has resulted from the discovery of an abnormality of the peroxidase enzyme system in the brains of children with Batten's disease. This results in an accumulation of a yellow pigment called ceroid lipofuscin in the brain cells producing slow destruction and progressive deterioration. These changes are quite similar to the changes that take place in all brains as they age. Thus, effective treatment for Batten's disease might delay the normal aging process.

Considerable effort in the last year has been directed toward improving upon a blood chemistry test to identify children with the disease and their carriers.

Additional studies have been done on the Kopang dogs which have a disease similar to Batten's disease in humans. For example, several defective puppies have been injected intra-arterially with crystalline peroxidase. These studies have shown that the blood brain barrier can be penetrated.

Of course, much additional work must be done before this technique may be utilized by humans.

Thus, we must continue to make funds available to continue with this vital research to better elucidate the pathophysiology of the disease, assist with genetic counseling, and initiate and evaluate therapy such as feeding or injecting peroxidase and/or various antioxidants.

It has been found, for example, that horseradish and avocado are high in peroxidase. It is possible that pure enzyme may be obtained from the placenta or from DNA-altered bacteria.

Research is the only way to solve this disease and prevent the devastating tragedy in families who have children so afflicted and effect tremendous savings to society as a whole.

The cost of care for each child is enormous and may be as high as $100,000 a year. Thus, 10 children such as these would cost more per year than the funds we are requesting.

Because of the constraints on time, I cannot give you a complete agenda, but there are 33 institutes throughout the world that are working on Batten's disease. If funding is provided, the chances of development of a specific treatment program in the foreseeable future appear to be very good.

We were, however, extremely disappointed that last year the Appropriations Committee made no mention of Batten's disease, although in the appropriation bill for 1981–82, the wording was as follows:

"The Committee * * * expects the Institute to expand its research on Batten's disease and related areas within the limits of high quality research available."

We feel it is extremely important for the NIH to have some strong direction into the type of research it supports. Thus, it is fitting that the final appropriations bill contain wording identical or similar to that quoted above.

For fiscal year 1983, there were only two grants from the NIH which were specifically related to Batten's disease, one for $91,000, and the other was for $59,000. Incidentally, the latter was not for a study in the United States.

We do not believe that the National Institute of Neurological and Communicative Disorders and Stroke should be so independent and so hallowed that direction cannot be given to them with respect to encouraging and sponsoring research on Batten's disease.

It is discouraging and counterproductive to have our researchers apply for Federal grants on Batten's disease and be turned down time and time again for lack of funds.

Thus, it is our firm recommendation that you provide a line item request, that at least $700,000 be used for research on Batten's disease for fiscal year 1985. This is the bare minimum in order to keep research progressing in this important field, and I would venture to say that the money would be well spent and you will get more for your $700,000 than many other appropriations.

That is our little pitch to get a line item. In the past—it has been very helpful for NIH in the past because they do go, somewhat, on the direction of Congress if they feel there is interest in the disease, they are willing to expend money for it.

Thank you.

Senator WEICKER. Thank you. We will take a look at it.

STATEMENT OF KEMP CLARK, M.D., PRESIDENT, THE SOCIETY OF NEUROLOGICAL SURGEONS, PAST PRESIDENT, AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS, CHAIRMAN, WASHINGTON COMMITTEE FOR NEUROLOGICAL SURGERY

PREPARED STATEMENT

Senator WEICKER. Dr. Kemp Clark, president, the Society of Neurological Surgeons, and past President, American Association of Neurological Surgeons.

[The statement follows:]

STATEMENT OF DR. KEMP CLARK

I am Kemp Clark, Professor and Chairman of the Division of Neurological Surgery at the University of Texas Health Science Center at Dallas. I have the honor of serving as President of the Society of Neurological Surgeons. I am a Past President of the American Association of Neurological Surgeons. Currently, I am also the Chairman of the Washington Committee for Neurological Surgery.

I would like to call your attention to the request from FY 1984 House Appropriations Committee for a report from the Director NINCDS concerning the feasibility of establishing new Stroke Clinical Research Centers. Importantly, it also is a call to initiate demonstration studies at existing centers to speed the application of stroke research results to clinical practice in the community. I quote from that report. "The Committee is concerned about the decline in the number of stroke clinical research centers as well as the planned reduction overall for funding in clinical research for stroke. Therefore, the Committee urges the NINCDS to maintain and to strengthen clinical research in stroke and has restored funds cut from the NINCDS to provide for additional continued support for the stroke clinical research centers." I hope that you will lend your support for recommendations for funding commensurate with the impact of this devastating disorder on our citizens.

Some data concerning this national problem are:

> There are almost 200,000 new stroke patients in the United State each year.
>
> Stroke is the foremost cause for disability and the third leading cause of death among adults in our nation.

One third of these patients afflicted are 65 years of age or less, many were employed.

Approximately half of these victims do not have hypertension or other easily identifiable risk factors that would distinguish those high risk from those at low risk.

About one half of these people die within a month after its occurrence.

The survivors join the ranks of the 9 million Americans who are disabled by stroke.

Hospital beds for chronic disease are becoming filled with disabled stroke victims.

At least two other people are required for the care of each disabled stroke victim.

The direct costs of stroke are estimated at over $8 billion per year. Indirect costs secondary to loss of earning capacity are even greater.

The degree of grief and suffering for the victim and the family is incalculable.

The manpower for stroke prevention is in desperately short supply.

Currently the research dollars allocated from all sources including NIH, NINCDS, NHLBI, and private groups is about $25 million a year.

This health problem is especially critical for our aging population. It must be addressed at the national level. The Committee must be aware that stroke as a cause of patient death and disability will continue to rise in the United States as the population ages. Therefore, it is imperative to effect a reduction in its cost, that prevention, education, and research be applied to this public health problem.

Increased funding, designated for stroke research and prevention, should be cost effective. Education of the public and demonstration to physicians of how best to treat patients with incipient stroke is a promising area.

Currently, prevention of stroke rests on the recognition of a transient ischemic attack. This is a reversible process, the individual develops neurological deficit which resolves in a short time. It is a matter of public education as well as physician responsibility, for the identification of the transient ischemic attack. Available today are a number of non-invasive techniques to determine whether or not the episode was produced by a treatable condition.

The second preventable type of stroke is that secondary to hypertension. A great deal of public education to insure compliance with medication is necessary to reduce the incidence of stroke from this cause. At this time, its treatment is poorly understood. Carefully controlled clinical research is warranted.

It is necessary that we capitalize on the any promising research leads which remain partially or unfunded. One important aspect of the stroke center would be the basic investigation to improve our ability in the treatment of stroke. Fundamentally, this requires looking at ways to protect the nerve cell in the absence or reduction of its blood supply.

There are several promising leads in this regard. The use of fluornated hydrocarbons as an additional source of oxygen to brain tissue is only one.

A rejuvenated national program, establishing a regional network for stroke research and demonstration centers would take direct advantage of the opportunities presently available. Further development of our knowledge would reduce both the incidence and the severity of stroke. An appropriation to NINCDS of an additional $5 million earmarked for Stroke Research Demonstration Centers would enable an additional 5 centers to be established, at the cost of $1 million per year per center. These funds would insure a critical mass to continue research, and the training of young investigators in basic and clinical research in stroke, as well as providing for public and physician education.

I'll be glad to answer any questions.

Dr. Clark. Thank you, Senator Weicker.

I am also the chairman of the University of Health Science Center at Dallas.

I would like to present to the committee the written testimony which I have already submitted. But first, I would like to thank the committee for allowing me to appear and to have heard Senator Javits' very eloquent plea for funds.

I specifically would like to address the committee on the issue of stroke and stroke centers. There has been a decline in the number of stroke centers in the United States, which was reversed by the Congress last year.

We would like to plead this time for an additional five such stroke centers. These centers should include not only clinical research in the maintenance of patients with stroke but the demonstration of the way that stroke can be avoided or prevented.

Finally, we would hope that these funds would enable some basic research in stroke. The principal problem of stroke at the moment is the ability to protect the nerve cell when the blood supply is diminished or impaired, and we have some very promising leads about how this might be done.

There are approximately 200,000 new stroke patients each year in the United States.

It is the leading cause of disability in adults. One-third of these persons who are stricken have their strokes when they're 65 years of age or less. Many of these are employed. One-half of these people die within 1 month after the stroke. We feel that the economic cost to the Nation, let alone the human suffering produced by this disease deserves specific attention, and we think that a stroke center aimed at a multidisciplinary approach in the treatment, prevention, and demonstration is an appropriate mechanism.

Again, I'd like to thank you for allowing me to appear.

Senator Weicker. Thank you very much, Dr. Clark. And we will take a very careful look at your testimony.

PREPARED STATEMENTS

Thank you for testifying. Your statement will be included in the record at this point, along with other statements submitted for the record on appropriations for the National Institute of Neurological and Communicative Disorders and Stroke.

[The statements follow:]

STATEMENT OF DR. LARRY L. EWING, PROFESSOR, SCHOOL OF HYGIENE AND PUBLIC HEALTH, JOHNS HOPKINS UNIVERSITY

The Endocrine Society is an organization of over 4,000 scientists and physicians devoted to research in Endocrinology -- the science that concerns itself with the biological functions of hormones and with the specific organs, the endocrine glands, that produce them. Briefly stated, hormones are chemical messengers that are secreted internally by the endocrine glands and carried to other parts of the body where they serve as nature's regulators of physiological function.

Some find it difficult to understand just what it is that endocrinologists do, because it is a science that is not identified with any particular disease. The fact is that a great many diseases, as well as a host of normal human functions, are intimately involved with the body's endocrine system. Diabetes, goiter, infertility, dwarfism, thyroid disorders and problems in menopause are all commonly recognized disorders of the endocrine system. The role of endocrinology in cancer research is firmly established, and new classes of growth substances that exert profound effects on cell growth, differentiation and division are increasingly being defined by endocrinologists and cell biologists.

Because endocrine disorders are frequently manifested in ways that are seemingly unrelated to hormonal activity, the contributions of endocrine research and treatment frequently go unrecognized. For example, as many as 20 million older Americans, most of them women over age 50, suffer from osteoporosis, a debilitating bone disease that predisposes the elderly to fracture. Such fractures often require prolonged hospitilization and create permanent disability.

Scientists have known for some time that the thinning of the bone associated with osteoporosis results from an endocrine disorder. Recently, an NIH advisory group made headlines by recommending that post-menopausal women use low-dose estrogen hormone therapy as the most effective means of preventing osteoporosis. Studies by endocrinologists were of major importance in arriving at this recommendation.

Another area of hormone therapy that has recently gained considerable attention is the treatment of dwarfism caused by the failure of the pituitary glands to release enough (or any) human growth hormone (HGH). For some years, limited supplies of HGH obtained from cadavers were made available for treatment through the National Hormone and Pituitary Program, which is operated by the University of Maryland with support from the NIH. About 2500 children across the country who suffer from dwarfism can be treated with HGH distributed by this program.

An exciting new product of research in endocrinology is the creation of synthetic HGH, using techniques of gene splicing. This holds the promise of substantially enhanced supplies, making possible the treatment of more victims of dwarfism and, in addition, the application of HGH therapy in other treatments, such as osteoporosis and burn therapy.

I would like to talk with you briefly about two programs of endocrine research being conducted at the institution where I am located, the Johns Hopkins University in Baltimore. The first involves research into the causes of Benign Prostatic Hyperplasia (BPH), which is the prostate problem unrelated to cancer that is so common in older men. Fully seventy percent of men 60 years of age and older suffer from this condition. It is the first leading cause of major surgery for men over 65. The costs resulting from treatment and work loss are estimated to be nearly one billion dollars a year. Nor are all the costs financial. Anyone who knows a man with such a prostate problem will very likely be aware of the pain, discomfort and frequent emotional strain associated with it. We are working on the causes of BPH at Johns Hopkins and we receive some support from NIH, but a good deal more can certainly be justified in view of both the high incidence of this disease among older men and the progress we have made to date.

We are also deeply involved in research in human reproduction. As you may know, this is an area in which endocrinologists have taken the lead, and we have made remarkable advances benefiting both infertile couples who desire to conceive, and those who wish to regulate normal fertility.

The program in which I am involved at Johns Hopkins is aimed at developing a safe, effective, reversible chemical contraceptive for males. We have tested a steroid combination of testoserone and estradiol in non-human primates that we think may meet these criteria. It appears to function effectively as a contraceptive, without undesirable side effects, and is reversible. Our current agenda includes pharmacokinetic studies to determine the proper dosage for human males.

These studies, too, are supported by NIH, in this case since 1970. It is work of proven value, but even with this record, and with a rather long history of support, we do not enjoy a very secure existence because of a constant concern that we will be caught in one of the periodic down cycles in NIH appropriations.

The budget for NIH proposed by the Reagan Administration for FY 1985 illustrates this problem. The proposed increase of only two percent over FY 1984 means that, even with the rate of inflation down, we will see a reduction in constant dollars for biomedical research and training. The treatment of NIH in the Administration's budget contrasts sharply with that afforded the Department of Defense, where an increase of 22% is recommended for research and development. I certainly hope that Congress will not go along with this disparity, for America's contributions to better health for millions of people in other nations will probably, in the long run, do more to enhance world peace and our own security than will the research in weaponry that the Administration so uncritically promotes.

It is important to view the consequences of the Administration's NIH budget in terms that go beyond a mere comparison of this year's versus next year's dollars. The budget will mean that less than one-third of all research project applications that receive approval through the rigorous NIH peer review system will actually be funded. Research training positions -- so vital to insure that medical science is constantly being renewed and stimulated by the new generation of researchers -- would decline by 9%, to 9000, well below the goal of 10,000 training positions that this Committee has set. The budget would mean, as well, no progress -- or even backsliding -- in such critical areas as clinical trials and renovation of deteriorating laboratory facilities at research establishments.

In brief, the Administration's budget for NIH for FY 1985 is woefully inadequate. The Endocrine Society has joined with a coalition of more than 100 research and educational organizations in the Ad Hoc Group for Medical Research Funding in recommending an increase for NIH of $647 million over the President's budget. I know that you have seen the Ad Hoc Group's brochure which details and justifies this recommendation, so I will not take your time to duplicate this information. Suffice it to say that this is not a large price to pay to continue the revolution in human well-being that modern medical science has wrought.

In conclusion, I do want to highlight the work of the two Institutes that are responsible for the majority of NIH support for research and training in endocrinology, the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases (NIADDK) and the National Institute of Child Health and Human Development (NICHD). We are also members of a separate coalition which has developed the rationale for a FY 1985 budget for NIADDK of $550 million, an increase of 18.9%, somewhat greater than that recommended for NIH as a whole, but justified by the need for NIADDK programs to regain the ground lost in past-year funding setbacks.

At NICHD, we propose an increase of $45 million, or 16.3%, rather than the retrogressive 1.8% proposed by the Administration. This will provide funding of about 37% of approved grants and permit the retention of current training programs, rather than reducing training positions by 15% as the Administration would require.

Finally, Mr. Chairman, I would like to express the appreciation of the members of my society -- and I am sure that this goes for tens of thousands of other American scientists, as well -- for the enlighted contributions that you and your colleagues have made to progress in medical science through your past support of NIH. It has often struck me that, of all the activities that we as citizens commission the Federal Government to carry out, the programs of NIH are perhaps the most altruistic. They are intended to benefit not only the health of our own people, but through the dissemination of medical knowledge and techniques, they work to improve the health of people everywhere in the world. We urge your continued and expanded support for these programs in the coming fiscal year.

STATEMENT OF RAYMOND A. CONNORS, PRESIDENT, TUBEROUS SCHLEROSIS ASSOCIATION OF AMERICA

My name is Raymond A. Connors, a Founding Director and President of the Tuberous Sclerosis Assn. of America (TSAA), and the parent of a child severely afflicted with Tuberous Sclerosis (TS).

We are happy to be here today and thank you for the opportunity to be heard. On April 29, 1983, the TSAA appeared before this Committee for the second time and made specific requests directed toward Tuberous Sclerosis research.

We are very pleased to report the following:

In September, 1983, an NIH/NINCDS program announcement entitled "Research Grants Related to Basic Mechanisms in the Phakomatoses" was published. The announcement mentions Tuberous Sclerosis as exemplifying the devastating effects these disorders have on affected individuals and families.

More recently, April 13, 1984, the first International Tuberous Sclerosis Research Workshop was held at the Mass. Institute of Technology, Cambridge, Mass. The Workshop was co-sponsored by the NIH/NINCDS and the TSAA. The objectives of the workshop included a review of currently available knowledge of the clinical, pathological and genetic features of TS; identifying promising investigational techniques in cellular and molecular biology, biochemistry and genetics, and forumulate relevant research questions that may be interdisciplinary in nature. A high priority of the Workshop was the development of a community of scholars interested in furthering the understanding of this disease. Results will be published.

This Association was impressed and pleased with the interest, concern and enthusiasm in the medical and scientific community regarding TS research. (We have attached a copy of those physicians participating in the Workshop program.)

Tuberous Sclerosis is one of the most common neuro-genetic disorders that devastates our children and the family unit. Throughout the U.S. (at this very moment) countless thousands of individuals and families are suffering from all the manifestations and problems related to TS. There are no centers that specialize in Tuberous Sclerosis research and the care and treatment of TS individuals.

It is well known that infants and children with Tuberous Sclerosis manifest problems in learning, behavioral abnormalities, hyperactivity, speech and language development, along with neurological and other clinical manifestations. Recognizing this, the TSAA recommends the establishment of multidisciplinary research center(s) for the purpose of investigating brain development and function in disorders of language, behavior, and learning in infancy and early childhood for the benefit of the unserved national population of Tuberous Sclerosis victims.

Finally, we understand that the proposed fiscal year budget for NIH is $4,556,453,000. We feel this budget should be increased to 5.5 billion dollars, and recommend that the National Institute of Neurological & Communicative Disorders & Stroke (NINCDS) receive at least 500 million dollars to carry on with its present programs and add new ones.

STATEMENT OF EDGAR OPPENHEIMER, ASSISTANT PROFESSOR IN PEDIATRICS AND NEUROLOGY, BOSTON UNIVERSITY SCHOOL OF MEDICINE AND BOARD MEMBER, TUBEROUS SCLEROSIS ASSOCIATION OF AMERICA

My name is Edgar Oppenheimer. I am an Assistant Professor in Pediatrics and Neurology at Boston University School of Medicine. I also serve on the Medical Advisory Board of the Tuberous Sclerosis Association of America (T.S.A.A.) and was Co-Director of the Tuberous Sclerosis (T.S.) Research Workshop which was held at the Massachusetts Institute of Technology on April 13, 1984. I am very grateful to have this opportunity to appear before you on behalf of the T.S.A.A. and would like to thank the Committee also for the interest and support that it has shown in T.S. in the past.

As you know, T.S. is an inherited disorder that may result in severe mental retardation, multiple physical handicaps, seizures, tumors in many organs and characteristic skin abnormalities. Recent studies have indicated that the prevalence of T.S. is greater than 1:10,000 people. It is likely that many additional individuals have this disorder with minimal manifestations. Nevertheless, these mildly affected individuals can pass on a severe form of the disease to their offspring.

The Tuberous Sclerosis Research Workshop which was held recently, co-sponsored by NINCDS and T.S.A.A., was enthusiastically received by approximately 140 attendees. Many other leading scientists and clinicians who were unable to attend in person have since requested copies of the proceedings of the Workshop. The T.S. research community is excited about the Workshop for it has identified a number of promising research directions which are fully feasible at this point in time subject to available funding. I have with me copies of the Workshop program, a list of invited participants and Workshop objectives for inclusion with this testimony.

I am here to plea on behalf of the victims of T.S. and their families that a fair portion of the taxpayers' dollars devoted to medical research be designated to directly fund research activity bearing on T.S.

It became very apparent during the recent Research Workshop that many of the basic scientific tools which are needed to carry out investigations of the basic mechanisms in T.S. are available and have already been applied to other neurologic diseases. Our immediate goal therefore is to apply these existing techniques to T.S.

In order to accomplish this goal,case material must be made readily available to the research scientists and to clinicians. In this regard, it was the consensus of the Workshop that the establishment of a National Tuberous Sclerosis Registry should be given highest priority.

We feel that a National Case Registry should be established in conjunction with the T.S.A.A. A proposal for setting up the Registry is currently being developed by Dr. H. Frederick Bowman of the Harvard - M.I.T. Division of Health Sciences and Technology and myself. The cost of initiating and running a viable T.S. Case Registry program is estimated to be approximately $250,000 for the first year. This cost includes correspondence with tens of thousands of physicians and health care providers who may be in contact with individuals with T.S. Ethical concerns such as informed consent, confidentiality and access to the information in the Case Registry are being addressed.

Following the establishment of the Case Registry we wish to develop a Multiproject ConsortiumResearch Application in order to facilitate the conduct of basic science research in T.S. The multiproject application will include a Clinical Core which will serve to gather clinical specimens for study by the various basic science research investigators (pathologists, biochemists, cellular and molecular biologists and clinical and biochemical geneticists). Investigators in the Clinical Core will make extensive use of the Case Registry to obtain clinical materials. Adequate facilities to coordinate the activicies of the Clinical Core such as preserving and disseminating tissue specimens for evaluations are needed. A conservative estimate of the cost of mounting the multidisciplinary consortium including the Clinical Core is approximately $1,300,000 per annum. This funding would pay for the Clinical Core as well as fund 6-8 separate basic science research projects.

Thus the total amount of support which we feel is needed to set up a Case Registry and to effectively utilize and mobilize existing investigators conducting relevant research is 1.5 - 2 million dollars per year.

In the process of organizing the Clinical Research Workshop we were extremely gratified to learn of the widespread interest in T.S. among scientific investigators of highest quality. We now exist in a unique point in time where there is both a developing momentum and a confluence of interest among investigators from different disciplines, advocating agencies, health care providers and members of Congress. We want to build on this momentum and continue our work.

We thank you for allowing us to present this testimony today and for the crucial role this Committee has played in helping to bring about the present favorable climate which hopefully will shortly lead us to a greater understanding of this dreaded genetic disorder. We look forward to the day when such understanding will make possible prevention of this disease.

Mr. Chairman, I trust that your Committee which has been so supportive in bringing us to this point will see fit to recommend a level of funding to NINCDS which will allow our proposed activities to be carried out.

SUMMARY

The following recommendations are requested by the Tuberous Sclerosis Assn. of America (TSAA) to add to present NIH/NINCDS activities:

1. That NIH funding be increased to 5.5 billion dollars, and that NINCDS funding be at least 500 million dollars.

2. That a minimum of $250,000.00 be set aside for the establishment of a National Tuberous Sclerosis Registry.

3. That a minimum of 1.5 million dollars per annum be set aside for the development of a Tuberous Sclerosis Muliproject Consortium Research Application in order to facilitate the conduct of basic science research in TS.

4. That there be established multidisciplinary research center(s) for the purpose of investigating brain development and function in disorders of language, behavior, and learning in infancy and early childhood for the benefit of Tuberous Sclerosis victims.

5. That the Tuberous Sclerosis Assn. of America (TSAA), when appropriate, be an active participant of any effort(s) initiated by this Committee on behalf of Tuberous Sclerosis.

STATEMENT OF DR. EDWARD S. COOPER, MEMBER, BOARD OF DIRECTORS, AND CHAIRMAN, AMERICAN HEART ASSOCIATION STROKE COUNCIL

Mr. Chairman, I am Dr. Edward Cooper, Professor of Medicine at the University of Pennsylvania School of Medicine. I submit this statement on behalf of the American Heart Association -- its 120,000 voluntary leaders, 40,000 scientific members and over two million program and fundraising volunteers. As a member of the Board of Directors of the American Heart Association, I am very pleased to have this opportunity to offer the following comments and funding recommendations for Federal programs pertaining to cerebrovascular disease research and prevention.

We are very grateful to the Labor, Health and Human Services and Education Appropriations Subcommittee for your consistent support of Federal programs in biomedical research, as well as those designed to facilitate the transfer of new scientific knowledge into public and private sector prevention and education efforts. Your continued support of these programs will help ensure a healthier future for all Americans.

The National Institutes of Health (NIH) is truly a national treasury of scientific and technological capability that, since mid-century, has brought our nation to a position of scientific leadership second to none in the world. The American Heart Association is pleased that its own programs in biomedical research, education and prevention also have contributed to this leadership.

Over the past four decades we have witnessed an unparalleled knowledge explosion in the biological and medical sciences. In our view, the scientists, administrators and managers at the NIH have succeeded to a spectacular degree in keeping its research programs abreast of these developments -- and frequently on their cutting edge. We are deeply concerned, however, that inadequate funding, rather than any lack of scientific opportunity or initiative, may slow the momentum of the expanded effectiveness in our nation's research enterprise.

The President's proposed increase of 2.2 percent for the NIH in FY 1985 falls far below the increases requested for other Federal research programs: National Science Foundation, 14 percent; Department of Defense, 15 percent; Department of Energy, 18 percent; and the National Aeronautics and Space Administration, 16 percent.

We urge the Subcommittee to recommend, for FY 1985, an increase of 16 percent over FY 1984 funding for the National Institutes of Health. This would (1) allow for real growth in the research programs of NIH; (2) encourage young M.D.'s and Ph.D.'s to pursue research careers by funding 10,000 NSRA fellows at increased stipend levels; (3) allow for the initiation of important new clinical trials and population studies; (4) begin to alleviate the serious problems of shortages and obsolescence in research equipment and instrumentation; and (5) allow for increased funding for the NIH Animal Resources Program .

We believe the public would support an increase of 16% over FY 1984 levels for all NIH programs. A recent Lou Harris Poll showed that 68 percent of those surveyed believes that Federal funding of basic research should be increased substantially. Furthermore, 82 percent indicated that even if basic research achieves no immediate results, it is worth the present investment.

The following are our recommendations for appropriations for the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), and specific comments on the biomedical research programs of the Stroke and Trauma Program of the Institute. Currently, I serve as Chairman of the Stroke Council of the American Heart Association. I also served for 11 years as Co-Director of the Stroke Research Center of the Philadelphia General Hospital, therefore I have had much personal experience in the stroke field.

There is nothing more tragic than to see a previously healthy, energetic person suddenly struck down and made permanently disabled because of a stroke. This is why the recent dramatic fall in stroke incidence has been particularly gratifying to workers in the stroke field, and similarly gratifying, I am sure, to the members of this Subcommittee and the American people as well.

Cerebrovascular disease is the third leading cause of death and the leading cause of long-term disability in the United States. Of the 500,000 Americans who suffer stroke each year, some 165,000 die. Stroke accounts for 8.3 percent of all deaths in the United States. Survivors of stroke now number almost 2 million. These persons often face years of severe physical and mental impairment, emotional distress and overwhelming medical expenses. It is for these reasons that stroke is viewed by many as the most devastating of all human disabilities. It is also one of the most costly of all disabilities -- each year, stroke and its consequences cost this Nation over $8 billion.

Black Americans especially are susceptible to cardiovascular disease. Black Americans are more likely than white Americans to suffer hypertension, which is a major risk factor in the causation of cerebrovascular disease. In fact, much of the progress made against stroke has come from advances in the diagnosis and treatment of hypertension.

While just a few short decades ago stroke was considered to be a hopeless disability, I am happy to report to you now that we are on the verge of great discoveries with regard to the prevention of stroke and the rehabilitation of stroke victims. The increased Federal support for biomedical research in cerebrovascular disease has lead to increased medical and scientific interest in the field which in turn has resulted in significant advances in the prevention and treatment of stroke. The identification of the major risk factors for stroke -- high blood pressure, atherosclerosis (hardening of the arteries), cigarette smoking, obesity and diabetes -- has aided in preventing the occurrence of the disorder. Also, the identification of transient ischemic attacks (a series of "little strokes" that often precede major strokes) has allowed for the provision of prompt medical and surgical attention that may prevent a fatal or disabling stroke. Advances in the treatment methods include new monitoring techniques -- telemetering and video methods -- for patients with stroke that allow us to study behavior and brain function; other continuous monitoring techniques, primarily positron emission tomography (PET) and nuclear magnetic resonance (NMR), provide vital information with regard to understanding and treating tissue damage caused by stroke; and new treatment methods have been developed that can be administered immediately after a stroke with the aim of minimizing its effects.

Thanks to these and other developments, progress against cerebrovascular diseases has been made in recent decades that is unparalleled in the world. From 1968 to 1981, the death rate from stroke has declined by 46 percent. When compared to the death rate from all other diseases -- 13 percent -- it is highly evident that the rapid progress against stroke is unique in medicine. However, we must not let stroke become a "forgotten disease" as it once was. Now, the challenge is even greater -- to prevent the future occurrence of stroke and its debilitating consequences.

The President's proposed budget includes $344.6 million for NINCDS which is only a 2.8% increase over the FY 1984 level of $355.1 million. This increase is well below the rate of inflation for biomedical research and development programs. With regard to NINCDS support for stroke research and research training, in 1984 the level is $24.3 million; under the President's proposed FY 1985 budget $25 million is allocated for stroke research. Again, support for the stroke program will only increase by 2.8% over the FY 1984 level. The President's budget would have a harmful effect on NINCDS programs in the following ways:

- The number of new and competing grants would be cut from 575 to 545; paylines would drop from 180 to 170 and the award rate would drop from 34 percent to 29 percent of approved grants. Also, each grant would be funded approximately 6 percent below study recommended levels.

- Non-competing awards would be funded approximately 5 percent below recommended levels.

- Training funds for individual fellowships and institutional awards would be cut by approximately $200,000.

- No new funds have been included for improvements in the stroke research centers program.

The NINCDS recently reported to Congress on the feasibility of establishing new stroke centers and expanding activities at existing centers. The report stated that "the field of cerebrovascular research is currently ripe for further development because of the availability of new information, approaches and technology." NINCDS indicates that an important step in taking advantage of the research opportunities presented at this time, based on current stroke research capabilities, would be the establishment of 12 additional stroke research centers and the initiation of nine 'demonstration units' at existing stroke centers, on a regional basis, to aid in the translation of stroke research findings into actual clinical practice.

The report estimates that the total cost in FY 1985 for establishing four of the 12 new centers and the nine demonstration units at existing centers would be $3.05 million ($800,000 for the centers and $2.25 million for the demonstration units). However, the Department has indicated that it does not endorse these recommendations "at this time" and the President's budget does not include funds to implement this plan.

The AHA believes that stroke centers play a vital role in the stroke research effort of NINCDS. Centers serve as highly productive research environments able to take advantage of the multi-disciplinary approach to research. Each center focuses on different research areas ranging from the etiological, clinical, diagnostic, therapeutic and basic pathophysiological processes with regard to the prevention and treatment of stroke. Examples of important stroke research currently underway at various stroke centers across the United States include the following:

- studies into more precise diagnostic procedures with regard to the different types of strokes (cerebral thrombosis, cerebral embolism, cerebral hemorrhage or aneurysm);

- studies into the pathophysiologic processes that result from the different forms of stroke and methods by which these processes can be alleviated or reversed;

- use of positron emission tomography (PET) and nuclear magnetic resonance (NMR) imaging techniques for displaying normal and abnormal chemical activities in the brain with precision;

- the discovery that the brain is more resistant to ischemia (deficiency of oxygen) than ever thought possible has lead to the investigation of early intervention techniques that can be administered after a stroke has occurred but before damage to the affected areas of the brain becomes irreversible;

- study of prostaglandins (active compounds in the brain derived from fatty acids in the diet) and their basic functions with regard to stroke and the biochemical events that take place in cells deprived of oxygen and nutrients;

- collaborative efforts between a neurologist and psychiatrist in one center with regard to stroke patients who also suffer major depression; and

- clinical trials for testing surgical procedures that bypass blocked blood vessels in the brain.

In order to further investigate the promising research areas listed above, to take advantage of emerging stroke research opportunities in the future and to encourage more qualified and innovative researchers to enter the field of cardiovascular research, we urge this Subcommittee to appropriate $388.8 million for NINCDS in FY 1985. Furthermore, we would suggest that the Subcommittee direct NINCDS, by statutory or report language, to establish four new stroke centers and three demonstration units at existing centers in each of the next three fiscal years, FY 1985 through FY 1987. The cost expanding the stroke research centers program would be approximately $1.55 million each year. Our recommended FY 1985 funding level for NINCDS of $388.8 million includes these costs.

In summary, we would urge that this Subcommittee accord a high funding priority for FY 1985 appropriations for the biomedical research programs of the National Institutes of Health by appropriating the following amounts for:

- THE NATIONAL INSTITUTES OF HEALTH -- $5,200,000,000 FOR ALL PROGRAMS.

- THE NATIONAL INSTITUTE OF NEUROLOGICAL AND COMMUNICATIVE DISORDERS AND STROKE -- $388,800,000 of which $1.55 million would be for the creation of four additional stroke centers and 3 stroke demonstration units at existing centers in FY 1985.

STATEMENT OF SHELDON M. WOLFF, M.D., ON BEHALF OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

Senator WEICKER. Next, Dr. Sheldon Wolff, chairman of the Infectious Disease Society of America.

Dr. WOLFF. I likewise have submitted a more detailed testimony, but I would like to summarize my testimony now.

[The statement follows:]

STATEMENT OF DR. SHELDON M. WOLFF

Mr. Chairman, and members of the Committee, my name is Sheldon M. Wolff. I have for the last seven years been Chairman of the Department of Medicine at Tufts University School of Medicine, and Physician-in-Chief of the New England Medical Center. From 1960 through 1977, I was privileged to serve at the National Institutes of Health. In 1968, I became Clinical Director of the National Institute of Allergy and Infectious Diseases, and Chief of its Laboratory of Clinical Investigation. I presently hold an NIH research grant and the department for which I am responsible conducts research under NIH grants and contracts that total several millions of dollars.

My testimony today is presented on behalf of the Infectious Diseases Society of America, an organization of medical and scientific researchers dedicated to the sharing of knowledge and the fostering of research in the area of infectious diseases. I am at present the Chairman of the Public Policy Committee, and I am past-President of the Society. We represent the overwhelming majority of infectious diseases specialists in this country and, in particular, those individuals involved in clinical and basic research in infectious diseases. Although I can hardly claim to speak for the entire microbiological and infectious diseases research community, I believe that my remarks would be representative of the position of virtually all of these individuals in this country.

I need not remind this Committee that the National Institute of Allergy and Infectious Diseases grew out of the original Hygiene Laboratory of the Public Health Service which began in the late 19th century. Thus, the NIAID has a long and wonderful tradition of support of research in areas of great importance to the American public. During the last 30 years, advances in understanding the epidemiology, microbiology, pathegenesis and treatment of infectious diseases has been extraordinary. A large portion of the credit for these remarkable advances can be clearly attributed to the generous support of the federal government through the National Institute of Allergy and Infectious Diseases.

Although many dreaded infectious diseases have been conquered, much, much more remains to be done. In fact, some of the most costly diseases, in both economic and human terms, are infectious in nature. Venereal diseases have killed more babies than the total number of deaths from Toxic Shock Syndrome, Legionnaires disease and AIDS combined. More frightening, perhaps, is the fact that certain strains of gonorrhea are completely resistant to penicillin. This raises the spector of an increase in infant deaths and further proliferation of a health problem that is already acknowledged to be epidemic.

Infections are also suspected of playing a role in immune-related diseases, such as Acquired Immune Deficiency Syndrome (AIDS). AIDS has an alarming fatality rate of nearly 90%. Yet, we still don't know for certain what causes this disease or how it is transmitted -- much less how it can be arrested or cured. People afflicted by AIDS typically die from unusual infections because their immune systems become irreparably defective. Although we can't yet be certain of anything, the breakdown of the immune system may be caused by communicable microorganisms, probably a virus.

NIAID supported scientists have discovered that many chronic diseases are caused by inapparent virus infections. For example, the discovery of the delta agent "incomplete virus" that had previously eluded detection may provide the key to treating severe hepatitis. Similarly, chronic infections from the hepatitis B virus have been associated with the development of cirrhosis and cancer of the liver. This debilitating infection can however be prevented in many cases by proper immunization. Moreover, by using recombinant DNA technology to produce the needed vaccine scientists can vastly improve upon the current method of production which is both expensive and time consuming.

The NIAID is responsible for many other exciting and life-saving research advances:

- Development of recombinant DNA and hybridoma technologies, much of which was pioneered by NIAID supported scientists, has enabled scientists to study human cells at the genetic molecular level.

  This has far-reaching consequences for our future ability to diagnose, prevent and treat many different diseases. In addition, recombinant DNA has spawned a multibillion dollar biotechnology industry that has contributed significantly to our nation's physical and economic health.

- NIAID scientists are hailing the emergence of a new generation of vaccines which will help to prevent costly and dreaded diseases such as hepatitis B, rabies and genital herpes. The new vaccines are manufactured by combining live viruses to produce new more effective recombinant vaccines.

The NIAID budget for FY 1985 put forth by the Administration will not allow that Institute to take advantage of extant scientific opportunities. Adoption of the Administration's budget in fact would be devasting:

- The number of competing research grants would fall by 15 percent below the FY 1983 level; while the average cost of a grant will experience less than 5 percent real growth over the same time period.

- The number of researchers to be trained will fall by 40 positions below the 1983 level. Training new researchers is key to the continued vitality of the research enterprise. Ignoring the future consequences of declining support for research trainees will not make this problem less severe or more reparable. Investments in research training are investments in the future of research.

- No new funds are provided for high priority clinical trials on the influenza vaccine, rotavirus vaccine -- the most important worldwide cause of diarrhea -- or vaccines for Group B streptococcal infections, just to name a few. Delays in initiating these trials will simply retard our ability to effectively prevent these diseases.

It is undeniable that infectious diseases extract a heavy price. Nearly one-third of all patients who seek medical care from a physician do so because of an infectious, allergic or immunologic disease. Infectious diseases alone result in 27 million patient days of hospital care at a cost of some $6 billion.

What is most frustrating is that many of these diseases can be prevented, and in fact, could disappear much the way smallpox has, if we are willing to support the necessary research and research training. However, we cannot look to the private sector to underwrite the costs of basic research. You, the Federal Government, are the only source for such funds.

And, the work supported by the NIAID cannot move forward without your support. The Administration's recommended increase in the Institute's budget amounts to 3.6% over last year. Mr. Chairman, the Congress in its wisdom provided the NIAID with a generous 12.5% funding increase last year; it was one of the largest increases awarded to any institute. Yet, because the NIAID has been under funded for so long, even the 12% increase did not stem the drift downward of the Institute's payline and award rate. The NIAID still has the lowest paylines of any Institute. What this statistic means in human terms is that an abundance of outstanding research proposals are going unfunded. These proposals, and the researchers behind them, are being denied the support they must have it they are to remain in the field of infectious diseases research. Frankly, upon analysis of the President's budget, researchers might well decide that chances of being supported by the NIAID are so small that they should pursue another field of research. Fortunately, most biomedical scientists are not that pragmatic.

Clearly the NIAID's budget must be increased beyond a meager 3.6% if it is to exploit numerous scientific opportunities. The goal must be to bring the Institute's payline up to that of its sister institutes, which is approximately 180. On the other hand, we recognize the futility of recommending an increase in appropriations for fiscal year 1985 that would accomplish this goal. Instead, we recommend a funding level that would result in a raise in the payline to 170 in 1985, and would pave the way for an increase to 175 in 1986 and 180 in 1987. The 1985 funding required to achieve step one of our goal is $346 million or a 10% increase over the current level.

In our view, our request reflects nothing more than an effort to respond to the basic needs of the Institute and is a reasoned approach to assuring that our research efforts in infectious diseases remain comparable to our efforts in other areas.

Mr. Chairman, I would be pleased to answer any questions. Thank you.

Dr. Wolff. I presently am the chairman of the Department of Medicine at Tufts University School of Medicine and physician-in-chief of the New England Medical Center. I worked at the National Institutes of Health for 17 years and in 1968, I became Clinical Director of the National Institute of Allergy and Infectious Diseases. I am presently a member of the Advisory Council to the Institute.

My testimony today is presented, as you said, on behalf of the Infectious Diseases Society of America. We represent the overwhelming majority of infectious disease specialists in this country and, in particular, those individuals involved in clinical and infectious disease research.

During the last 30 years advances in understanding the epidemiology, microbiology, pathogenesis and treatment of infectious diseases has been truly extraordinary. A large portion of the credit for these remarkable advances can be clearly attributed to the generous support of the Federal Government through the National Institute of Allergy and Infectious Diseases.

Although many dreaded infectious diseases have been conquered, much, much more remains to be done.

The NIAID budget for fiscal year 1985 put forth by the administration will not allow the Institute to take advantage of many scientific opportunities. Adoption of the administration's budget, in fact, would be devastating:

The number of competing research grants would fall by 15 percent below the fiscal year 1983 level, approximately.

The number of researchers to be trained will fall by 40 positions below the 1983 level. Training new investigators is key to the continued vitality of the research enterprise. Investments in research training are investments in the future health of this country.

No new funds are provided for high-priority clinical trials on the influenza vaccine, the rotavirus vaccine—the most important worldwide cause of diarrhea—or vaccines for group B streptococcal infections, just to name a few.

The payline of the NIAID would remain at approximately 160—the lowest of any Institute of the NIH.

It is undeniable that infectious diseases extract a heavy toll. Nearly one-third of all patients who seek medical care from a physician do so because of an infectious, allergic or immunologic disorder. Infectious diseases alone result in 27 million patient days of hospital care at a cost of some $6 billion annually.

What is more frustrating is that many of these diseases can be prevented, and in fact, could disappear, if we are willing to support the necessary research and research training. We cannot look to the private sector to underwrite the costs of basic research. The Federal Government is the only significant source for such funds.

Clearly, Mr. Chairman, the work supported by the NIAID cannot move forward without the support of the Congress. The administration's recommended increase in the Institute's budget amounts to 3.6 percent over last year. Last year, the Congress provided NIAID with a generous 12.5 percent funding increase last year, one of the largest increases awarded to any institute. However, since the NIAID has been underfunded for so long, even this generous increase did not stem the drift downward of the Institute's payline and award rate. What this statistic means in human terms is that an abundance of outstanding research proposals are going unfunded.

These proposals, and the researchers behind them, are being denied the support they must have if they are to remain in the field of infectious disease research.

Clearly, the NIAID's budget must be increased beyond a meager 3.6 percent if it is to exploit the numerous scientific opportunities presently available. The goal must be to bring the Institute's payline up to that of its sister institutes, which is approximately 180.

On the other hand, we recognize the futility of recommending an increase in appropriations for fiscal year 1985 that would accomplish this goal. Instead, we recommend a funding level that would result in a raise in the payline to 175 in 1985, and would pave the way for an increase to 180 in 1986. The 1985 funding required to achieve step one of our goal is $362 million, or roughly a 15-percent increase over the current level.

In our view, our request reflects nothing more than an effort to respond to the basic needs of the Institute and is a reasoned approach to assuring that our research efforts in infectious diseases remain comparable to efforts in other areas.

Again, thank you, Mr. Chairman.

Senator WEICKER. Thank you, Dr. Wolff. I appreciate your testimony.

STATEMENTS OF:

BARBARA H. LAYMAN, PRESIDENT, THE ASTHMA AND ALLERGY FOUNDATION OF AMERICA

JORDAN N. FINK, M.D., PRESIDENT, THE AMERICAN ACADEMY OF ALLERGY AND IMMUNOLOGY

PREPARED STATEMENTS

Senator WEICKER. Barbara Layman, president of the Asthma and Allergy Foundation of America.

Your statements will be placed in the record in their entirety.

[The statement follows:]

STATEMENT OF BARBARA H. LAYMAN AND DR. JORDAN N. FINK

Mr. Chairman. My name is Barbara Layman. I am the mother of a severely allergic child. I am also President of the Asthma & Allergy Foundation of America, a non-profit organization dedicated to the cure, control, and eventual prevention of these diseases, while improving the quality of life of the 35 million men, women, and children who currently suffer from them. The Foundation has numerous chapters throughout the country. All of them are fueled by volunteers, as well as by patients and parents, who work hard to overcome asthma and allergies while helping others do the same.

With me is Dr. Jordan N. Fink. Dr. Fink is President of the American Academy of Allergy and Immunology. The Academy is the nation's largest professional society of scientists and practitioners in these fields, with a membership of over 3,000 here in the United States and 41 countries abroad.

Both the Foundation and Academy are working hard toward one common goal: the eradication of asthma and allergic diseases. These diseases are among the nation's most common, costly, and misunderstood health problems. They afflict at least 35 million Americans: approximately one out of every six Americans suffers from at least one of these disorders. Conservative estimates indicate 9 million Americans suffer from asthma, with or without hay fever; another 15 million have hay fever alone, or allergic reactions to food, drugs, or insect stings. More than 6 million of these sufferers are children who have at least one allergic disease, and many have more than one.

High as these figures are, they reflect only the number of people who currently suffer from asthma and allergies. They do not record those who have had reactions in the past, but have since "recovered". For example, of all Americans living today, about 15 million have had, have, or will have asthmatic episodes.

Americans suffering from asthma and allergic diseases spend in excess of $2 billion each year for physicians' services, drugs, and hospital and nursing home care. While severe allergic reactions can cause death, most allergic illnesses are of a chronic nature that leads to restricted activity and loss of work and school time. America's asthma sufferers spend a total of 35 million days in bed each year because of the disease. The indirect costs for allergies such as wages lost because of illness - are more difficult to calculate, but they exceed $800 million a year for asthma and hay fever alone.

Research is our only hope for the effective control of these diseases and hopefully, their prevention altogether. That is why, Mr. Chairman, we have brought our concerns before this Subcommittee today. We strongly believe the President's proposed budget for the National Institutes of Health (NIH) falls dangerously short of this nation's research needs, and may jeopardize the pace of scientific progress not only for asthma, allergies, and other immunologic diseases, but for all other health problems facing this country today.

Simply put, our message is clear - and addresses three issues relating to increased support for medical research.

NATIONAL INSTITUTE OF HEALTH

We strongly endorse the Ad Hoc Groups for Medical Research recommendation for increases amounting to $647 million over the President's request. We truly believe that research is not a light switch which can be turned on and off. Training of a researcher takes 5 - 8 years. Research results require years, if not decades, to come forth.

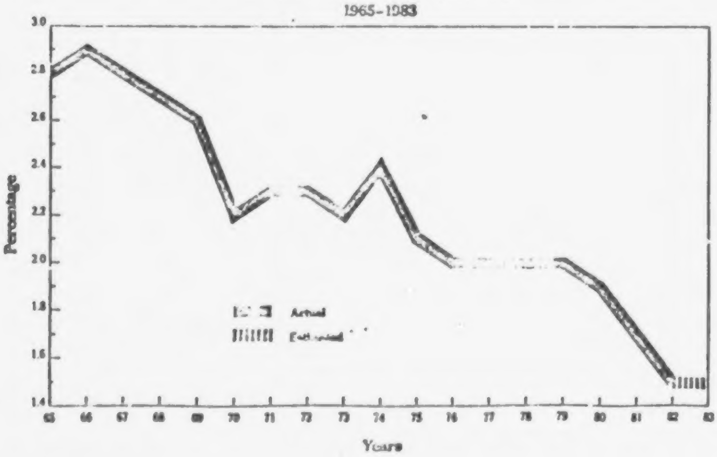
The point is, research is not only a humane program, it is exceptionally cost effective for jobs, stability of our schools, and a prime means of health cost controls.

During the last decade when Medicaid and Medicare have jumped from about $12 billion to today's estimates of over $70 billion, we have been putting less emphasis on health R & D research.

The chart that follows is from the Ad Hoc groups booklet. As one can see, the line should be going in just the opposite direction. Health research leads to prevention programs and effective cost saving treatments.

Federal Support for Health R & D as Percentage of Total U.S. Health Spending

1965–1983



IMMUNOLOGY PROGRAMS

Second, we strongly urge you to continue and expand the initiative of the immunology programs started last year. We recommend that report language be developed directing the NIH to place more resources in this area and reporting back to you what they plan to do by way of this initiative.

Last year Congress started an initiative in the immunology programs at the NIH. This initiative is critical. Immune system research is conducted at nearly every Institute with just about one-half of the efforts being carried on at the National Institute of Allergy and Infectious Diseases.

We would like to describe for you the immune system and its importance so that the wide ranging effects can be better understood.

The immune system is a complex network of specialized organs and cells that has evolved to defend the body against attacks by "foreign" invaders. When functioning properly, it fights off infections by agents such as bacteria and viruses. When it malfunctions, however, it can unleash an enormous variety of diseases, from allergy to arthritis to cancer.

The immune system developed because we live in a sea of microbes. Like man, these organisms are programmed to perpetuate themselves. Because the human body provides an ideal habitat for many of them, they try to break in; and because the presence of these organisms is often harmful, the immune system will attempt to bar their entry or, if they succeed in getting in, to seek them out and destroy them.

The immune system, similar in complexity to the intricacies of the brain and nervous system, displays several remarkable characteristics. It is able to distinguish between "self" and "nonself". It is able to remember previous experiences, and react accordingly; once you have had the mumps, your immune system will prevent you from getting it again.

The success of this system in defending the body depends on an incredibly elaborate and dynamic regulatory-communications network. Millions and millions of cells, organized into sets and subsets, pass information back and forth like clouds of bees swarming around a hive. The result is a sensitive system of checks and balances that produces an immune response that is prompt, appropriate, effective, and self-limiting.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

Third, and finally, we recommend that a strong emphasis be placed on the National Institute of Allergy and Infectious Diseases.

With its mandate of work on the Immune System, Asthma, Allergies, Acquired Immunological Deficiency Syndrome (AIDS), and its impact on nearly all diseases, this Institute is truly a sleeping giant - especially in terms of its potential economic impact due to prevention efforts.

Try to imagine the emotional and economic impact of effective vaccines against allergies, cancer viruses, multiple sclerosis, AIDS, and arthritis. This is not a pipe dream - it can and will someday be a reality.

Some important facts to be considered are:

- Payline at the NIAID (160) is the lowest at the NIH.

In order to raise the payline to the NIH average of 180, +$43,000,000 over the president's request is required for Research Project Grants.

- The Centers' program at NIAID would be reduced below the 1981 levels.

The Centers' are the major vehicle in this country for translating and disseminating our research findings to physicians and patients.

We urge restoration to at least the FY 1981 level of 20 Centers, as well as expansion to other parts of the country. In this way, the nation as a whole can benefit from the Centers' very important research and effective outreach activities. An excellent example is the self-management of asthma program that was recently demonstrated with children and their families and has been shown to reduce emergency room visits. Therefore, we are asking you to support a +$1,223,000 increase over the President's request.

We recommend that language be included relating to the Centers' programs as well as the importance of continuing high priority outreach and education programs.

Research Career Awards under the President's request should be elevated to levels of the mid-1970's. We simply ask for restoration of awards to 120, the 1978 level. This would require +$2,000,000.

In spite of their critical importance in strengthening medical school faculties in the basic and clinical studies on the immune system, biotechnological advances and molecular biology, all of which are of direct importance to NIAID's mission, Research Career Awards have been sacrificed to maintain their commitments to the Research Project Grant Program.

Training - the long and short term life blood of all research programs is also being cut by the President.

We request an increase of +$2,700,000 for an additional 135 training positions which will help reverse the negative message young students have been receiving about the lack of commitment the government has shown for research and training.

All told, we support an increase of approximately $55,000,000 to $60,000,000 for the NIAID. This is an increase of about 15 percent over the President's budget - but still in line with a 14 percent increase for the National Science Foundation (NSF) and 22 percent increase for the Department of Defense-related Research and Development that the President has proposed.

NATIONAL HEART, LUNG, BLOOD INSTITUTE

Occupational lung diseases, including asbestosis and occupational asthma, are among the leading causes of respiratory disorders in the United States. We would urge you to include language in your committee report for this institute strengthening and expanding research programs related to all respiratory diseases caused by occupational exposures.

The magnitude of the problem is immense - yet our goal for cures and prevention programs are achievable.

In summary, the goals, opportunities, and support requested by AAFA and AAAI will not be satisifed by the status quo. The proposed federal budget for fiscal year 1985 allows for little growth at all. To insure that biomedical research can be carried out in the effective manner that the cause demands, Congress should fund NIH with an eye to "real growth". A provision of funding at a given percentage above the inflation rate for high priority projects will help maintain the momentum of our biomedical research effort. We urge the Subcommittee to give serious consideration to this concept. In any civilized society, commitment to the eradication of disease should be demonstrated in deed as well as in word.

Thank you, Mr. Chairman and members of the Subcommittee, for you thoughtful consideration of our recommendations. We stand ready to work with you in preserving and strengthening this nation's struggle against asthma and other allergic and immunologic diseases, as well as all diseases which afflict mankind.

Mrs. LAYMAN. Thank you, Mr. Chairman. My name is Barbara Layman. I am from Waynesboro, PA, and I am the mother of a daughter, who's now 22. She was hospitalized 26 times. Fortunately, because of good care and good medicine, she has not been in the hospital for some time and is doing very well in leading a normal life. And that is what I wish for all of our people.

I am president of the Asthma and Allergy Foundation of America, and we are a nonprofit organization representing the asthma and allergic patient.

With me today is Dr. Jordan Fink and Dr. Phil Norman from Baltimore. We have chapters around the country. We are fairly new and we are growing by leaps and bounds.

Both the foundation and the academy are working hard toward one common goal and that is the eradication of asthma and allergic diseases. These diseases are among the most costly diseases in the country, and that is one thing that the foundation is trying very hard to do, to educate people. Although people take allergy fairly lightly, it is very serious and even causes death. Thirty-five million Americans are afflicted. Approximately 1 out of each 6 suffers from one of these disorders. Conservative estimates indicates 9 million people suffer from asthma alone. That doesn't count hay fever, the deaths from bee stings, et cetera.

More than 6 million of these sufferers are children. And they not only have one allergic disease, most of them have more than one.

High as these figures are, they reflect only the number of people who currently suffer from asthma and allergies. I, for example, have been first presented with asthma at the age of 40, and I've seen people as late as 50 or 60 or 70 suffer from asthma.

The really staggering thing is the people who suffer from asthma and allergic disease spend over $2 billion each year for treatment. While severe allergic reactions can and do cause death, most allergic illnesses are of a chronic nature, and that means that people's activities are restricted, a lot of school time is lost. Children lose more time to asthma and allergic disease than any other, and many work-hours are lost. Thirty-five million days are spent in bed trying to recover from asthma and allergic diseases. The indirect costs for allergies such as wages lost because of illness are more difficult to calculate, but they exceed $800 million a year.

Research is our only hope. I have seen great strides in my 4 years as national president, and I am looking forward to an increase at our institute and at NIH, in general, so that we can continue to go forward in this very, very important process.

Thank you. Dr. Fink, would you like to add something?

Dr. FINK. Yes, Barbara. I'm president of the American Academy of Allergy and Immunology, which represents over 3,000 allergists and immunologists in this country. We strongly support the ad hoc group for medical research funding, and we urge the committee to increase the appropriation to bring NIH expenditures up to a percentage as it has been of health care expenditures. As you can see, the percent of expenditures has been decreasing. We also urge that you raise those expenditures to at least 15 percent, which is commensurate with all the R&D expenditures of the other important agencies of the Government.

Immunology is our major forte. And as you may be aware from current television and newspapers, immunology is coming more and more to the forefront in the 1980's; breakthroughs every day, especially with the news about AIDS and the virus and the ability to diagnose coming very quickly, based on immunological research supported by the Federal Government. Immunology cuts across all institutes, and it's this kind of research which we see going on which will provide answers to other diseases, whether they be infectious, cancer, neurologic diseases, as we've heard this morning.

We especially support the National Institute of Allergy and Infectious Diseases which needs an input of dollars to continue its work in the fields of allergy, infectious diseases, cancer, AIDS, et cetera. As you heard, the payline of NIAID is the lowest in the institutes. It's at 160, and the necessary infusion of dollars to increase that commensurate with its sister institutions is 180.

The center's Outreach Program has been reduced, and we urge that it be reinstituted for the one additional center research career awards, which provide an academic basis in the medical school for the teaching and research in this important area. We request a restoration to the level of 120 from the current 70. We have to strengthen our medical schools. Only one-half of our medical schools have programs in allergy and asthma diseases. Training is very important, and we request funds, we request NIH be allowed funds to get students into this important area.

Finally, we urge that the National, Heart, Lung, and Blood Institute be provided resources to study important occupational diseases, occupational asthma, and other occupational respiratorial disease.

Thank you for hearing us.

Senator WEICKER. Thank you.

Mrs. LAYMAN. We have some information we'd like to pass on to the committee about this.

Senator WEICKER. The next witness is Jacqueline Bellanti, national chairperson of the National Coalition on Immune System Disorders.

STATEMENT OF JACQUELINE R. BELLANTI, CHAIRMAN, NATIONAL COALITION ON IMMUNE SYSTEM DISORDERS

Ms. BELLANTI. Good morning, Senator. I am Jacqueline Bellanti, and I am chairman of the newly formed National Coalition on Immune System Disorders.

With me today are some of the members from the steering committee, and I'd just like to take a few seconds to have them introduce themselves.

Ms. BOYLE. I am Marcia Boyle, president of the Immune Deficiency Foundation.

Ms. PRICE. I'm Andrea Price of the Lupus Foundation.

Mr. TURNER. I'm Win Turner, and I represent the Multiple Sclerosis Society and the coalition.

Ms. BELLANTI. You may perhaps wonder what such a diverse group of individuals might have in common, that we would have at least an opportunity to find a common bond to come together. I'm very happy to tell you that the thread that binds us is the human immune system and the science of immunology. And I suppose by the time these particular hearings are over, immunology will be another word you'll be able to say without much difficulty—like otolaryngology.

The national coalition now is a committee that is composed of 12 voluntary and professional health organizations, including the Immune Deficiency Foundation, Lupus Foundation of America, the Arthritis Foundation, the American Academy of Allergy and Immunology, the Asthma and Allergy Foundation, National Multiple Sclerosis Society and the National Association of Area Agencies on Aging, and the American Diabetes Association and the Gay Rights Lobby.

One of the things that has brought us together, as I said, is the study of the human immune system and the research on the immune system and infectious diseases, which is where we really feel the input to answering a lot of questions lies for the future, and therefore, in order to promote research and services on these areas, there has been formed this national coalition. It is primarily an educational force, both for ourselves, internally, and also for being able to establish a liaison between our voluntary organizations and that of the administration and also by trying to promote and encourage the coordination of immunological efforts throughout the NIH and through the National Institute of Allergy and Infectious Diseases.

As you know, the immune system is a marvelous component when it is all working right. And it is the defense that our body has against all kinds of infections. When it is not working right, when there are certain things that are going wrong with it, we have a variety of diseases from simple allergies up to and including cancer.

The proposed budget for 1985 is well below what the coalition feels that the immunology initiative would be able to gain any kind of input for the future, and as members of the Ad Hoc Group for Medical Research, we are proposing the increase of $647 million over the President's budget. This will provide the necessary funds to continue initiatives, and since every Institute at NIH conducts some immunology, the 1984 budget of $452 million is already on immunology programs. And as we know, there have been marvelous inputs into the future; however, I think because of the fact that perhaps the most frustrating thing for young researchers today is to spend a tremendous amount of time gathering together research projects and have it go through peer review, only to have it approved, but not funded, we're worrying about the loss of researchers for the future.

Training has already been discussed and is also in a critical state.

And the career awards. Last year, there was identified, the NIAID research career awards, as one that should be given high priority. And in order to continue this revitalization and research, it also has to be continued.

Last year the committee in its report specifically created specific immunology programs, especially in the area of information and coordination. The coalition asks that this be continued and requests report language calling for a symposium of scientists to review the state of the art and to give both short- and long-range programs, in order to coordinate research throughout the NIH.

PREPARED STATEMENT

So, therefore, this coalition has been working throughout this past year, and for the record, I would like to state that included in our testimony that has been provided there are summary statements from each of the organizations on the steering committee, as well as the steering committee members and addresses, and also statements from each of the steering committees, the Immune Deficiency Foundation, the Arthritis, Lupus, Multiple Sclerosis, American Diabetes Association and the area institutes on aging. If there is any information I can provide the committee on, I would be happy to. I wish to thank you for the opportunity for the coalition to present its first testimony.

Senator WEICKER. Any information that you can provide the committee we would be very happy to receive. And we are happy for the coalition to present its first testimony.

Well, I thank you very much. We will look at it in detail.

[The statement follows:]

Statement of Jacqueline R. Bellanti

My name is Jacqueline Bellanti, Chairman of the Steering Committee of the National Coalition on Immune System Disorders. This Steering Committee is composed of 12 voluntary and professional health organizations including the Immune Deficiency Foundation, Lupus Foundation of America, Arthritis Foundation of America, American Academy of Allergy and Immunology, National Multiple Sclerosis Society, National Association of Area Agencies on the Aging, Asthma and Allergy Foundation of America, American Diabetes Association, and Gay Rights National Lobby. One might ask what such a seemingly diverse group of organizations representing multiple diseases and disorders might have in common. The tie that binds us is the human immune system and the science of immunology.

MISSION STATEMENT OF COALITION

Our mission statement is as follows: Current research indicates that a wide variety of diseases, disorders, and infections are caused by infectious agents and deficiencies or defects in the immune system. Immunologic and infectious disease research have the potential for preventing, treating, and possibly curing seemingly disparate diseases such as rheumatoid arthritis, lupus, multiple sclerosis, diseases of the lung, cancers, asthma, various allergies, and immune deficiency dieseases (e.g., agammagolobulinemia, AIDS). Thus, research on the immune system and infectious diseases has a profound potential for affecting the health and quality of life for millions of Americans.

Therefore, in order to promote research and services to this vitally important area, there is created a Coalition on Immune System Disorders.

The Coalition, representing a broad spectrum of organizations interested in biomedical research on, and treatment of, immune system disorders is formed for the purposes of: (1) focusing the attention of the Congress, the Administration, and the general public on the kind and nature of disease and disorders affecting the human immune system; (2) establishing a mechanism for general liaison among the interested voluntary health agencies, professional associations, and advocacy groups, and the National Institute of Allergy and Infectious

Diseases and other NIH institutes; (3) promoting and encouraging the coordination of immunologic and infectious disease research efforts, including the exchange of research and service information throughout the National Institutes of Health and other federal agencies; (4) providing a forum for organizations to discuss their common interests and share information; and (5) informing the Congress and the Executive Branch of the variety of needs for research and services related to the immune system and of appropriate levels of Federal funding to meet those needs.

IMMUNE SYSTEMS

The immune system is a complex network of specialized organs and cells that has evolved to defend the body against attacks by "foreign" invaders. When functioning properly, it fights off infections by agents such as bacteria and viruses. When it malfunctions, however, it can unleash an enormous variety of diseases, from allergy to arthritis to cancer.

The immune system plays a major role in human health and disease. It is only in the last several decades that scientists have begun to uncover its secrets. Immunologists will continue to gain insight into possible ways to manipulate the machinery of the immune system so that, someday, they may be able to "adjust" its components, stimulating the malfunctioning ones into effective action and depressing the hyperactivity of others. Immunology is an exciting and fast moving discipline and vital to all biomedical research.

We come to you now as a Coalition of vitally interested and concerned organizations with our recommendations which we believe will greatly enhance the new initiative begun last year and will allow this effort to be continued and expanded.

NATIONAL INSTITUTE OF HEALTH

As a member of the Ad Hoc Group for medical research, the Coalition strongly endorses the recommendations of that group.

The proposed increase of $647 million over the President's Budget request will provide the funds necessary to continue the initiatives on the immunology programs. It is important that such an amount be percentage wise distributed to immune systems programs throughout the National Institutes of Health.

Every Institute at the NIH conducts research on the immune system. In 1984, $452 million will be spent on immunology programs. The President's Budget is proposing that it be increased by $19 million in Fiscal 1985, or only 4%.

The following is a breakdown by institute of where the money is being spent.

NIH FUNDING OF IMMUNOLOGY RESEARCH
(Dollars in Thousands)

INSTITUTE	FY 1981	FY 1982	FY 1983	Estimated FY 1984	President's FY 1985	Optimum (FY 1985 PJ)
Allergy	$84,181	$ 87,581	$106,418	$118,970	$124,667	$155,000
Cancer	92,342	93,896	103,426	109,640	115,313	133,313
Heart	43,500	50,000	53,000	59,800	61,000	70,300
Dental	6,318	5,403	7,335	7,935	8,411	9,111
Arthritis	48,892	49,610	60,720	72,865	75,500	95,200
Neurology	8,238	8,747	13,061	14,700	15,100	20,000
General	3,200	3,400	4,000	4,500	5,000	5,000
Child	12,861	13,666	16,808	18,200	18,700	22,000
Eye	9,176	10,160	11,953	13,138	13,400	15,275
Environment	2,381	2,889	2,379	1,959	2,600	2,600
Aging	4,669	4,883	6,694	7,863	8,127	9,909
Resources	15,900	16,108	21,066	23,315	23,481	28,130
TOTAL	331,658	346,343	406,860	452,885	471,299	565,838

NIAID

The Coalition considered the following areas to be of critical concern, and ones that must be addressed if we are to adequately and appropriately enhance the initiative of the immunology programs.

Research Project Grants

- NIAID has the lowest payline at the NIH, 160. The range among the Institutes is 160-220. Under the President's FY 1985 request, the NIAID payline will remain at 160 and the award rate will be further reduced to 28% of approved applications. In FY 1985, many excellent, and meritorious research project grant applications will go unfunded. This is a very discouraging message to send to young scientists and physicians about to embark on research careers. We, like all Americans, are concerned about the rising deficit. Therefore, we are not asking for support of a 220 payline for NIAID, but rather suggesting a conservative payline of 180 which reflects an award rate of 39%. This requires an estimated $43,043,000 increase over the President's Request.

Training

- Training is in a critical state despite the fact that it is considered to be the lifeline of basic and clinical research and the source of new and renewed vitality, ideas and innovative approaches to removing barriers to new and improved methods of diagnosis, treatment and prevention of disease. To begin to relieve the shortages which continue to exist in basic and clinical pediatric allergy and immunologic diseases, we strongly urge your support for a $2,723,000 increase over the President's Request. This increase would allow NIAID to support an additional 135 fulltime training positions, thereby sending a positive message to those indiividuals about to embark on research careers under the purview of NIAID.

Research Career Awards

- Last year, the Congress identified the NIAID Research Career Awards program as one that should be given high priority. It was emphasized that these awards provide mid-career support for medical scientists and are a key to developing vigorous research groups at medical schools specializing in infectious diseases.

Under the President's Request, the NIAID will not have the resources required to revitalize its research career program to the extent necessary to meet the growing need for expanded research programs in infectious, allergic, and immunologic diseases. We ask that the Congress restore the number of career awards to 120, which is the number funded in FY 1978 and FY 1979, and would require an additonal $2,248,000.

Congressional Initiatives

Last year, your Committee, in its report specifically created an initiative on immunology programs - especially in the area of information and coordination of programs at the NIH.

We ask you to continue this initiative at the NIH and request report language calling for a symposium of scientists to review the state of the art, create plans and coordinate research programs and the involvement of international research findings.

The Coalition, representing a broad spectrum of organizations vitally interested in biomedical research on, and treatment of, immune systems disorders, feels that the President's Budget Request is inadequate to meet the needs of the immunology initiative begun by the efforts of Congress last year. We strongly support increased efforts in immunological research because of its importance and potential benefit to all Americans.

Thank you, Mr. Chairman and members of the Subcommittee for the opportunity for the Coalition to testify and for your serious consideration of our recommendations. The Coalition stands ready to assist you in this most important mission.

(NOTE.—Additional material is in the subcommittee files.)

STATEMENT OF HON. JAMES ROOSEVELT, FORMER REPRESENTATIVE FROM CALIFORNIA, ON BEHALF OF THE NATIONAL COMMITTEE FOR RESEARCH IN NEUROLOGICAL AND COMMUNICATIVE DISORDERS

PREPARED STATEMENT

Senator WEICKER. Before moving on to the American Neurological Association, we have one witness left from the National Committee for Research in Neurological and Communicative Disorders and that is the Honorable James Roosevelt.

Congressman, do you want to step up to bat here. We are all ready to go. Your statement will be placed in the record before you proceed.

[The statement follows:]

STATEMENT OF JAMES ROOSEVELT

Mr. Chairman, I am honored to represent the National Committee for Research (NCR) today in presenting further arguments for the need for new levels of support for the National Institute of Neurological, Communicative Disorders and Stroke (NINCDS). NCR is a national coalition of 62 voluntary and professional organizations dedicated to increasing public support for research. Mr. Chairman, this is an unusual year for advocates of the Institute. There is powerful new support for the conclusion that now is the time when the disorders of the brain, of the nervous system and of communication can be healed.

The members of NCR are extremely grateful to Congress for responding to the opportunities before us; the Senator Jacob Javits Neuroscience Awards last year are an appropriate and fitting tribute to this leader.

With this gratitude is mixed frustration. While appropriations have increased significantly in the past few years, they do not approach funding the volume of approved grants piling up - grants from productive researchers to enhance our knowledge of over 600 diseases and disorders. We see the wealth of opportunity literally lying at our doorstep but are frustrated not just by economic realities but also by rigid formulas. This "formula approach" to NIH funding is too inflexible for the opportunities awaiting us.

These opportunities are forcefully spelled out in the outside evaluation of research opportunities undertaken by 25 prominent scientists through the Tracor-Jitco Company. The conclusion of this expert panel agrees with that of the voluntary and professional groups of NCR that now is the time to break the molds of formula and seize the opportunities before us.

In response to a Senate request in 1983 for a study of research opportunities, a panel of 25 experts in the basic and clinical neurological and communicative sciences has submitted a report to the Committee on Appropriations of the Senate.

These experts stated,

> We are on the verge of an important new revolution in medicine. We have within our grasp the information, the tools, and the human resources to take the final steps toward understanding how the human brain works and how to correct many of the disorders that affect it,

> and thus, to allow every human mind to realize its full intellectual and emotional potential.

They concluded their report,

> There is every indication that research and research training in the neurological and communicative science, if adequately supported by the Congress of the United States, will sustain and even accelerate the already exponential increase in our understanding and ability to alleviate - and indeed cure - neurological disease.

That panel of experts recommended a significant increase in NINCDS funding in FY 85 to approximately $667.86 million. This figure was not adjusted for non-competing research projects in the FY 84 budget. With such an adjustment the proposed figure is a recommendation of $579,462,000. The NCR Citizens Budget Committee and Board of Directors have reviewed the Tracor-Jitco report and agree with its recommended level of funding. This figure will allow NINCDS to fund over one-half of the approved research grants. While one-half is not very impressive of funding of approved grants, barely 35% currently receive funding.

Committee of Combat Huntington's Disease
Deafness Research Foundation
Dysautonomia Foundation
Dystonia Medical Research Foundation
Fellowship House
Freidreich's Ataxia Group in America
Gateposts Foundation
International Josephs Diseases Foundation
Muscular Dystrophy Association
National ALS Foundation
National Association for Hearing and Speech Action
National Ataxia Foundation
National Easter Seal Society
National Head Injury Foundation
National Huntington's Disease Association
National Multiple Sclerosis Society
National Neurofibromatosis Foundation

- National Office on Disability
- National Reye's Syndrome Foundation
- National Tuberous Sclerosis Association
- Parkinson's Disease Foundation
- Sertoma Foundation
- Spina Bifida Association of America
- Tourette Syndrome Association
- United Parkinson's Foundation
- Voice Foundations

Professional Societies

- American Academy of Neurological Surgery
- American Academy of Neurology
- American Academy of Otolaryngology
- American Association of Electromyography and Electrodiagnosis
- American Association of Neurological Surgeons
- American Association of Neuropathologists
- American Association of Neurosurgical Nurses
- American Electroencephalographic Society
- American Epilepsy Society
- American Neurological Association
- American Neurotogy Association
- American Otological Society
- American Paraplegia Society
- American Society of Neurochemistry
- American Society of Neuroradiology
- American Speech-Language-Hearing Association
- Association for Research in nervous & Mental Diseases
- Association for Research in Otolaryngology
- Association of University Professors of Neurology
- Child Neurology Society
- Congress of Neurological Surgeons
- Society of Neuroscience
- Society of University Otolaryngologists

Tourette Tic & Movement Disorders Foundation

Triological Society

Neurological and communicative disorders affect approximately 42 million Americans. The number affected will increase because of the aging of our population and the problems will become more severe because of expected increases in some disorders such as senile dementia, deafness, and brain tumors. Environmental factors such as chemical agents and noise may also increase the number of those affected.

There are over 600 identified neurological and communicative disorders, affecting millions of Americans, including approximately:

- o Half of the 1,300,000 patients in nursing homes in 1978 who were institutionalized because of dementia. By the year 2025, perhaps 17%-20% of the population will be over 65 years of age with approximately 3,000,000 requiring institutionalization because of some form of dementia.
- o 13.2 million who suffer from some type of hearing loss.
- o 7.5 million who have speech and language disorders.
- o 3 million schoolage children who suffer from hearing loss and 3.5 million who have speech impairments.
- o 2.5 million persons who are afflicted by strokes, the third largest cause of death in America.
- o One out of every ten children who suffers some noticeable nervous system impairment including learning disabilities, seizures, cerebral palsy, mental retardation, spina bifida, and autism.
- o Two million people who have epilepsy.
- o Half a million people who suffer from Parkinson's Disease.
- o 250,000 people who have multiple sclerosis.
- o 1,000,000 Americans who have had a spinal cord injury; two-thirds of these are persons under 35 years of age.

By any standard, not only are the numbers of those afflicted staggering but because of the nature of these disorders, extensive services are needed for many years. The current costs for neurological and communicative disorders is estimated to be $114 billion annually. In future years, the cost of caring for these individuals will be astronomical.

Mission of the National Institute of Neurological, Communicative Disorders and Stroke is to develop knowledge of how the central nervous system and the brain function, how dysfunctions and disorders come about and how they may be cured or ameliorated. If we can find the keys as to exactly how these most intricate of bodily systems function in a healthy state, we may then be able to find ways to prevent their becoming dysfunctional or unhealthy. This could assist society in working with every disorder from stuttering to aphasia to Parkinson's disease.

NINCDS has responsibility for the third and fourth largest killers in the United States: stroke and trauma. Its responsibilities encompass most of the handicapping conditions which cause massive budgetary outlays through the Education of Handicapped Children Act, Rehabilitation Services, Medicare and Medicaid. The resources of NIH devoted to the largest two killers, cancer and heart, are $1 billion and $635 million, respectively. Yet, the next two causes of death, stroke and trauma, receive only $40 million combined. In addition, NINCDS has received added responsibility from Congress in the Orphan Drug Legislation without any additional funds.

The major program divisions of NINCDS are:

Neurological disorders which includes the study of diseases such as epilepsy, senile dementia, multiple sclerosis and developmental neurological disorders;

Communicative disorders which explores the areas of speech, language and hearing impairments;

Fundamental neuroscience which is basic to the support of research of understanding the human brain.

Stroke and trauma which supports research services in such areas as brain and spinal cord injury and stroke.

The neurosciences are the general fields of research on the brain at all levels of analysis from the most fundamental biophysics and chemistry to the most complex analysis of thought. The neurosciences are among the most challenging of the biomedical sciences. This has been acknowledged by the report of the President's Biomedical Research Panel which singled out neurobiology as one of the five research areas meriting special emphasis.

Many technological advances have improved research techniques. The data gathered by non-invasive techniques such as the CAT scanner have increased the knowledge of anatomy and structural pathology of the brain. The development of PETT or Positron Emission Traverse Tamography has provided scientists the ability to view brain metabolism function in action. Discoveries in brain chemistry in the past five years have identified chemicals produced by the brain which are agents for important activity such as learning, speech, language, pain, emotion, and sexual behavior. Advances in anatomical and physiological techniques have increased knowledge of the complex circuitry of the brain which has provided new information in the study of speech, language and hearing development.

The communicative disorders research concerns areas that are, by far, the cost common of the disease disorder categories serviced by NINCDS - the sensory and communicative disorders that affect our ability to speak or hear. Basic and clinical research in communicative disorders show the urgent, rapid advance of relatively new sciences. The strength and promise have depended on prior advances in the electronic and microsopic technology and on basic advances in embryology and biochemistry. A great deal of progress has been made in the prevention or relief of disorders involving hearing and speech and in our rehabilitation of individuals with these disorders. This progress has been achieved in large measure through the support of research and training in the communicative sciences by NINCDS. The critical problem for hearing disorders concerns the intricate neurophysiology of the inner ear and its nerve pathway to the brain. The process of transduction, through which sound waves are transformed though motions of the canal fluids of the inner ear to neural signals, remains a problem for scientists but on its resolution hinge future treatments for what is called "nerve deafness," the most common type of hearing loss. Developments are being made in such areas as otitis media, hearing or balance loss from head injury, laryngeal cancer, laryngeal papilloma, stuttering, language development in childhood, aphasia or the loss of speech after stroke and voice disorders.

Mr. ROOSEVELT. I want to apologize for being out of order and late, but I find that our travel is not what I thought it would be. I arrived in Chicago at 3:30 this morning. I had a little bit of trouble getting here.

You have already heard from Dr. Rubin, and I don't think there is much point in my repeating what I know you and members of the committee know. I feel very strongly about it for personal reasons, as well as for the overall reasons that we feel so many are affected by what we are trying to accomplish, and that the time is now to try to put some of the events together so that we get some results. And it is results that in my humble opinion that are the things that you're looking for, as well as ourselves.

I've been particularly happy during this year, because we had the opportunity to have prominent scientists, the 25 prominent scientists make their report in response to the Senate committee's request. And it seems to me that that was of value to us, because it gave us an opportunity to get away from the special pleading in looking for an outside independent and wholly, we think, objective point of view.

I believe that also I might say that I'm sorry I wasn't here to hear Senator Javits this morning. He's an old friend. And while we always didn't see eye to eye politically, I think he's an example of tremendous courage. And I just would like to say that I wish I'd been here to hear his testimony also.

The 25 scientists who came up with a figure—it's really exactly the same as the figure which our independent citizens budget committee has come up with. Whether we have approved their finding, whether they're approving ours is something else. The $579 million, which is the adjusted amount for noncompeting—or adjusted to the noncompeting research projects in the fiscal year 1984 budget. I think that's the figure we'd like to stick with and to back.

I am always struck by the fact that we presently do about 35 percent of the currently approved grants, which is not in itself a very impressive figure, percentagewise. The amount of $579,462,000, would bring us up to about 50 percent. That certainly is a good step forward, even though it isn't the ultimate that we would see accomplished.

Mr. Chairman, I personally feel, and this is speaking for the NCR at this point, I would like to say that we feel we have had in America a wonderful sympathetic understanding and intelligent effort to go forward in a field where the human element is so strong. And I would like to pay my tribute to you and your committee and to the general attitude of the Congress, because I believe in somewhat difficult circumstances they have done their very best to go forward and to make progress, at a time when sometimes the opposite direction was somewhat indicated.

If I may, sir, I would like to now be excused and extend my thanks to you for your courtesy.

Senator WEICKER. So I know that you were able to come to Washington 1 month ago, and you were able to testify in these matters. We appreciate your testimony here. You certainly do a fine job, a first-class job of representing so many people, and we appreciate your being here.

STATEMENT OF E. DARRACOTT VAUGHN, JR., M.D., CHAIRMAN, RESEARCH COMMITTEE, AMERICAN UROLOGICAL ASSOCIATION

PREPARED STATEMENT

Senator WEICKER. The next witness is Dr. E. Darracott Vaughn, Jr., chairman of the American Urological Association Research Committee.

[The statement follows:]

STATEMENT OF DR. E. DARRACOTT VAUGHN

I am E. Darracott Vaughan, Jr., Chairman of the Division of Urology at The New York Hospital-Cornell Medical Center and Chairman of the Research Committee of The American Urological Association. I am presenting this testimony on behalf of The American Urological Association whose membership of 5,800 represents the majority of American Urologists. I also represent the American Association of Clinical Urology and The Society of University Urologists.

This testimony is a new endeavor of the American Urological Association and we would like to thank you for this opportunity to inform you about areas of Urological disease which warrant federal support for biomedical research. I believe that our first task is to define clearly the activities of a Urologist.

The Urological community cares for patients of all ages with disorders of the genitourinary tract which includes the kidneys, ureters, bladder, prostate, urethra, adrenal glands and male genitalia. Specific disorders include cancers of the prostate, bladder, kidney and testis, urinary tract infections, renal stones or calculi, prostatic enlargement, neurologic disorders of the bladder, incontinence, infertility, impotence, genitourinary congenital anomalies, obstruction of urinary flow and trauma. These are some examples of the diverse areas which fall under the purview of Urologists. It is apparent that we treat patients of all ages from the neonate with potentially life-threatening kidney failure due to obstruction of urine flow to the octagenarian with a similar situation due to prostatic enlargement, benign prostatic hypertrophy. It is also clear that the Urologist will become increasingly important as the average age of the American population increases and there are more patients with incontinence, prostatic enlargement, both benign and cancerous, neurogenic bladder disease and impotence.

The diversity of our activities serves as a challenge to Urological investigators. I would like to devote a few moments to relate several areas of advancement in urologic research resulting from federal support before making specific recommendations.

In 1979 Congress mandated the support of Specialized Centers for Research in urolithiasis, kidney stone disease. This intensified effort has led to a better understanding of the mechanism which causes this entity which afflicts 1 per 1000 Americans each year resulting in considerable morbidity and economic loss. One result of this support in urolithiasis has been the introduction this year of two effective drugs which combat stone formation and growth. Moreover, new techniques have been introduced recently which facilitate renal stone removal without a traditional kidney operation. These include the whole new field of "Endourology" whereby small tubes are directed into the kidney using x-ray localization with subsequent stone destruction and removal. In addition, shock waves can be generated and focused on kidney stones and with repeated impacts the stones can be destroyed without any surgical intervention.

However, these advancements also lead to new challenges. For example, we need more complete information concerning the factors which facilitate the passage of a stone fragment from the kidney to the bladder. The neurophysiology of the ureter is incompletely understood.

I would also like to call your attention to cooperative studies now under way in Europe and the United States to define which children will incur renal damage from congenital anomalies which allow urine to reflux back up to the kidney. The outcome will identify which children are at risk and need corrective operations. In addition, we are gaining critical information which explains how bacteria gain access to the bladder and then ascend to the kidney to cause renal damage. Surface structures called fimbria or pili enable the bacteria to attach and subsequently establish an inflammatory reaction which may be responsible for renal scarring. There is potential for drugs to prevent either sticking of the bacteria or the inflammatory action hence protecting against the effects of infection.

In the area of cancer, we continue to improve our ability to detect tumors by radiographic studies, detection of abnormal cell characteristics, and "markers" of tumor activity in the blood and urine. For example, it has recently been shown that cells from kidney and bladder tumors exhibit antigens which potentially could be found in either blood or urine by new "monoclonal antibody" techniques.

Similarly, our ability to treat genitourinary cancers is improving. Multidrug chemotherapy is capable of curing over 85% of young men with testis cancer and other forms of chemotherapy are proving effective in patients with metastatic bladder cancer.

However, it is critical that there is increased effort directed toward the understanding of the causative factors leading to the formation of genitourinary cancers.

Finally, in the area of benign prostatic enlargement which afflicts many American men as they grow older, there is early information suggesting intracellular male hormonal imbalance and abnormal prostatic cell growth factors. Once these basic cellular characteristics are defined then it will be possible to influence the behavior of these cells and affect growth.

These are but a few examples of present activities in Urological Research which are being generated through federal research support.

Despite the gaps of information necessary to understand Urology related disorders, there has been little growth in the number of research awards and funds for research in Urology during the past three years. One problem is that Urological related research tend to be diffusely "buried" within larger research programs in a number of institutes. Accordingly, six institutes at the NIH (National Institute on Aging - NIA; National Cancer Institute - NCI; National Institute of Allergy and Infectious Disease - NIAD; National Institute of Child Health and Human Development-NICHD; National Institute of Neurological and Communicative Disorders and Stroke- NINCDS; and the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases - NIADDK) support Urology related research. Hence, this strength of the discipline, its diversity, becomes a detriment without appropriate coordination. At present only one of the six institutes at NIH supporting urological research has a separate program to administer these awards.

Recommendations:

1. That the Congress recommend formation of a coordinating committee or council consisting of representatives from each institute involved in research relevant to Urology under the leadership of the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases - NIADDK, which presently has a Urologic program.

Productive growth of Urological Research is also contigent on adequate appropriations for both NIH as a whole and NIADDK. The Urological community is concerned with the proposed budget for 1985. Current projections assuming only a 2.8% increase would result in an actual decrease in both competing and non-competing grants as well as center grants. At a time of increasing need for Urological research and increasing potential for advancement, these reductions could result in an actual decrease in Urological funding.

Recommendation:
2. That the total appropriation to The National Institute of Health be $5,213.9 million and

Recommendation:
3. That the total appropiation for NIADDK be $550 million.

Dr. VAUGHN. Mr. Chairman, I am chairman of the division of urology of the New York Hospital-Cornell University Medical Center and chairman of the research committee of the American Urological Association, which represents the majority of urologists in this country. I also represent the American Association of Clinical Urology and the Society of Clinical Urologists.

We have testimony that we would like to have submitted for the record.

Senator WEICKER. It will be included in the record.

Dr. VAUGHN. I would like to speak informally.

Thank you for this opportunity to discuss with you some exciting areas for potential research funding. I think our first task is to clearly define the activities of urologists, since it is a first visit.

The urological community cares for patients of all ages with disorders of the kidneys, ureters, bladder, prostate, urethra, adrenal glands, and male genitalia. Specific disorders include cancers of the prostate, bladder, kidney and testis, urinary tract infections, renal stones or calculi, prostatic enlargement, neurologic disorders of the bladder, incontinence, infertility, just to name a few.

It is apparent that we treat patients of all ages from the neonate with potentially life-threatening kidney failure due to obstruction of urine flow to the octagenarian with a similar situation due to prostatic enlargement, benign prostatic hypertrophy.

Moreover, new techniques have been introduced recently which facilitate renal stone removal without a traditional kidney operation. These include the whole new field of endourology whereby small tubes are directed into the kidney using x ray localization with subsequent stone destruction and removal. In addition, shock waves can be generated and focused on kidney stones and with repeated impacts the stones can be destroyed without any surgical intervention.

However, these advancements also lead to new challenges, because we really do not have any idea how the small stones pass from the kidney to the bladder. That is neurourology.

We are also gaining critical information on how bacteria gain access to the bladder, they stick. This is the cause of cystitis in females, and perhaps once we explain how these pili or organelles and sticking occur, we can better define inflammatory reaction and have drugs that prevent this sticking or the inflammation.

In the area of cancer, we continue to improve our ability to detect tumors by radiographic studies, detection of abnormal cell characteristics and markers of tumor activity in the blood and urine. The most exciting field, I think, is recognition that there are subsurface antigen in the kidney and urinary tract which now can be identified by monoclonal antibody techniques. But there is recent data which suggests that we may be able to develop bladder and urinary tests for very early detections of these malignancies and thereby treat these patients earlier.

Finally, in the area of benign prostate enlargement which affects many of the senior male members of our population. There is evidence of intracellular male hormonal imbalance and abnormal prostatic cell growth factors. Once these basic cellular characteristics are defined, then it will be possible to influence the behavior of these cells and lead to more rational treatment.

These are but a few examples of the diversity in the areas of urological research.

Despite the gaps in information that are presently available, there is very little growth in the area of research grants in urology over the past few years.

One of our programs which I would like to see addressed is the fact that urologic-related research tends to be diffusely buried within at least six other institutes within the National Institutes of Health.

Hence, this strength of the discipline, its diversity, becomes a detriment without appropriate coordination. Only one of the six institutes at NIH supports a special program in urologic research.

I would like to suggest that Congress recommend the formation of a coordinating committee consisting of representatives of each institute involved in research relevant to urology under the leadership of the National Institute of NIADDK, which, as I stated, has a present program.

Finally, productive growth in urologic research is something that we must have. The urology community is concerned with the proposed budget for 1985, with the current projections assuming only 2.8 percent in competing and noncompeting grants, which will actually be a decrease.

Therefore, we recommend that the total appropriation at NIADDKD be $550 million. And the total appropriation of the National Institutes of Health be $5.2 billion.

Thank you very much.

Senator WEICKER. Dr. Vaughan, thank you very much.

Next is Roberta Devito, of the American Brittle Bone Society. Roberta, why don't you have your friends join you?

STATEMENT OF ROBERTA DEVITO, AMERICAN BRITTLE BONE SOCIETY

Ms. DEVITO. That may be very important because my son wants to run for President.

Senator Weicker. Why don't you introduce your family?

Ms. DeVito. This is my 8½-year-old son, named Conje, named after his dear departed Italian grandfather, and my daughter Anna Marie, who is 9½.

Thank you very much for letting me come. I really appreciate it so much. It is a real big privilege and the best civic lesson that a young person could have.

My son had the opportunity when he was about 4 to make a short statement in the House, and since then I think that is what has more or less encouraged him in this direction.

Senator Weicker. That is probably the first and last sure statement that was made.

Ms. DeVito. I can vouch for that. He says that he will mark a little bit of time being a Senator until the big day comes to him.

I am here not only to talk about my son's disease, brittle bone disease. I am here to talk about osteoporosis, which, in a good number of cases, there is an underlying metabolic bone disease.

There is a widespread enthusiasm for bioclinical and biomedical research of osteoporosis, and there is an emerging interest and excitement, as you can well imagine in the pharmaceutical and projects development field.

One in four women or more will lose bone from their skeleton, excessive enough to cause fractures on average by age 62. I am here to ask your help in developing a solid interest in research in osteoporosis, an affliction which affects, by Government numbers, 15 million people, most of them elderly women.

I am here to say that this is too serious a problem to delay the major effort even 1 more day. To this end you have helped tremendously, and I want to point out that at the beginning of the month you had a standing room only consensus development conference on osteoporosis, sponsored by NIH, and you really had to be there, as the saying goes, to see just how much has been learned and is continuing to be learned, and you also just in the last year developed a very nice, informative pamphlet for the lay public which we distribute with your blessings.

Osteoporosis has silently advanced to great numbers in our society now. It has burst into the health arena with near epidemic strength. And, as medical science continues to help us live a little bit longer and as a dramatic change in the population occurs, and the baby boomers get up there, and they live longer, we are going to have a really big problem, to put it mildly.

This is exactly why modest increases in the budget for osteoporosis will not do. In fiscal year 1983 you spent a little over $3 million. That is the most current year that I have figures for, and I am asking to really quadruple that figure to show a real serious interest.

It costs us all in a very direct way because most of the millions of elderly with osteoporosis are in the age group covered mainly by Government health care programs with hundreds of thousands of fractures every year due to osteoporosis specifically, we estimate it to cost $1.5

billion annually. The typical woman at risk for developing osteoporosis is small boned, fair complected, and postmenopausal. If she has had early menopause, biologically or surgically, so much the worse.

I would like to direct your attention to a letter that is green in your packet that is from a son very concerned for his mother, and I would like to also say that I have a retired Alabama schoolteacher who can't even get bladder surgery that she needs for fear that the time on the surgical operating table will cause more compressions, fractures, and press fractures of the spine.

I will say that many steps can be taken by the young if they only know to do it, and to this end I would ask that you encourage NIH, especially NIADDK to work with the Brittle Bone Society and our network of volunteers to develop an education program that we might take to the schools. We have recieved support for this idea from some members of the NEA, the National Education Association.

In the biomedical field much has been learned, and I would like to say that much has been reported at this meeting that I attended earlier this month. But so much has been heard that one physician at the end of the conference remarked to a colleague, "Just what is osteoporosis?" And it was certainly a rhetorical question, but I think it reflects the truth of much that lies ahead, and we are here to ask your help for osteoporosis as well as the disease my son has, which is slightly different from osteoporosis in that it affects the whole body.

My son is the reason that I represent several thousands with this disease called osteogenesis imperfecta. He is quite intelligent, and is in an intellectually gifted program in Pennsylvania. As I told you, he wanted to be President, but he is one of the more fortunate ones.

And I am going to read from my testimony, just to conclude. A 6-year-old girl, in south Jersey, weighed 7 pounds, 5 ounces at birth, now weighs 16 pounds at age 6 and cannot yet hold up her head. She suffers from multiple fractures every week, every few weeks from no trauma that you would ever recognize. She breaks an arm, her vertebra, and her pelvis with just a sneeze.

My son has had 90 broken bones. This little girl is lying in Atlantic City Hospital right now with all these fractures, and her lungs are filling up with fluid because of congestive heart failure.

Just when we think we have found some answers, the questions change. Just last night the mother phoned me and wanted to know could I help her. I put her in touch with a consultant that we use right here in Washington, DC. We play the role of education, and although I am happy to provide this service there is not enough information and the children are still dying, and we do need help desperately.

I would like to say that you have spent a tremendous amount of money on this disease, $775,000, in fiscal year 1983, and I would like you to continue to maintain this.

Thank you very much.

Senator WEICKER. Thank you, and we will take a very hard look at your suggestion.

Do you have anything you want to add to your mom's testimony?

Master DEVITO. Well, someday I would really like to become President, and I am already starting my campaign. [Laughter.]

So you better watch out.

Senator WEICKER. I have a feeling you are just going to be elected. I really do. So we will make sure we get the research for you, and we need you. OK.

Ms. DEVITO. We need you, too. Thanks for all your help.

PREPARED STATEMENT

Senator WEICKER. OK. We will insert your statement in the record at this point.

[The statement follows:]

STATEMENT OF ROBERTA DEVITO

SUMMARY OF RECOMMENDATIONS

Funding and Incentives for Osteoporosis and Osteogenesis Imperfecta

I am recommending that Congress initiate an aggressive drive at the N.I.H., and in particular within the N.I.A.D.D.K., to equal the widespread enthusiasm for biomedical and clinical research of osteoporosis and to match the emerging interest and excitement in the pharmaceutical and products development fields. N.I.H. funding of osteoporosis research for FY '83 (the most current year for which figures are available; see attachments) was $3,001,898.

The time is at hand when all possible resources must be channelled into osteoporosis. I suggest that emphasis must be put forth promptly in order to evidence a serious commitment. I recommend that $14 million be included in the N.I.H. budget for osteoporosis, an amount not as much an increase as it is a result of recognizing a serious problem and wanting to combat it.

Using cost figures for the five major fractures most commonly experienced by post-menopausal women, the cost per year for treatment of these fractures is about $1.5 billion. And it seems certain that the actual number of fractures will increase as the population ages because people live longer. Increasing survival is going to have a large economic impact on the health-care system, particularly since this age group is covered mainly by government health-care programs.

After five years of major focus on osteoporosis, I recommend that N.I.H. sponsor, for the purpose of providing a progress report to Congress, a Consensus Development Conference on Osteoporosis.

I recommend that Congress suggest that the N.I.A.D.D.K. work with and through the American Brittle Bone Society to develop, produce, and distribute audio-visual and print material aimed at educating teenage young women about osteoporosis and the lifelong measures they must take to help prevent the early onset of osteoporosis in later years.

I recommend that N.I.H. funding for osteogenesis imperfecta in FY '85 be maintained at the FY '83 level of $755,000 plus an increase to offset any rise in the cost of doing business.

However, I recommend that all previously uncommitted monies be poured into the O.I. - related cardio-pulmonary syndrome and into the O.I. - related growth deficiency syndrome and into various aspects of osteogenesis imperfecta which appear to be a result of accelerated aging.

I recommend that funding be allocated to develop and produce a car-chair for a dwarfed adult with O.I. which would be safe, comfortable, and appropriate. I also recommend that appropriate exercise equipment be developed and produced, to aid in weight-bearing and to aid cardio-pulmonary function , designed for the special needs of osteogenesis imperfecta.

In addition, I recommend that the N.I.A.D.D.K. elicit a nationwide response from physicians attending the death of any person with osteogenesis imperfecta by requesting that they name it on the death certificate as the secondary cause of death. This will aid in developing statistics as to the number of deaths attributable to osteogenesis imperfecta.

In conclusion, I recommend that in FY '83 Congress maintain its traditionally strong support of the N.I.H. in general, and particularly the N.I.A.D.D.K. Recognizing that biomedical research is interdependent, I support an N.I.H. budget of $5,213,900,000 with $550 million of it for the N.I.A.D.D.K.

I am Roberta DeVito, president and the founder of the American Brittle Bone Society. It is my privilege to appear before you as I do, representing the concern of many millions of older Americans who will develop some degree of osteoporosis, particularly the one in four women or more who will lose bone from their skeleton excessive enough to cause fractures, on average, by age 62.

Since 1978, when I first appeared before this Committee, I have asked for your help in iniating a solid interest in researching this affliction, and you have helped with the result that N.I.H. has more than tripled their funding of osteoporosis. (See attachment for FY '83 figures.)

But, it is not enough. It is never enough, I know you must be saying. It's true. But we don't mean it in an unkind way. Ask the diabetes folks; they ask for increasing amounts, not because they feel that money thrown at a problem will solve it, but because they, and we, know that much good research is going unfunded. Many strides and advances have been made in the area of diabetes because of your support; now we feel that we must ask for the same serious commitment for osteoporosis.

First, let me thank you for all that you have done to encourage more attention to be focused on osteoporosis and, also, osteogenesis imperfecta. Within the past year, the N.I.A.D.D.K. has published a very good pamphlet on osteoporosis for the lay public and is in the process of completing one on osteogenesis imperfecta. And just at the beginning of this month, N.I.H. sponsored a "standing room only" Consensus Development Conference on osteoporosis. As the cliche goes, "You had to be there . . ." So much information was presented that by the end of the first day, I overheard one physician exclaim to a colleague, "Just what is osteoporosis!" Of course, it was more of a statement than a real question, but it signifies the state of the art. At the end of another osteoporosis symposium in Philadelphia the following week, one noted physician in the field remarked to me that, in the light of the papers presented that day, it was clearly uncertain which women should be treated at all and, if so, with which therapies.

Osteoporosis progresses silently until the first fracture. And like the disease, osteoporosis has silently advanced until it has now burst into the health arena in near-epidemic strength.

This is exactly why modest increases in the present budget for osteoporosis will not do. This is why we ask your help in creating a commitment to this disease that will show the upwards of 15 million people now osteoporotic (N.I.A.D.D.K. figures) that you recognize this is too serious a problem to delay major effort even one more day.

Osteoporosis costs us all. It costs us about $1.5 billion annually, because this age group is covered mainly by government health-care programs. Clearly, osteoporosis is among the leading diseases in the elderly, particularly elderly women.

The "typical" woman at risk for developing osteoporosis is thin, small-boned, fair-complected, is post-menopausal. If she has had an early menopause and has a family history of osteoporosis, so much the worse.

There are any number of small helps a woman can give herself to prolong the onset of osteoporosis, if she only knows about them. They include dietary and supplemental intake of calcium, yearround daily exposure to sunlight's rays, weight-bearing exercise such as walking a mile a day, and, oh yes, using a rocking chair when sitting (so as to keep active).

We are in some control of our health destiny, if we but only know. This is why I am requesting that Congress initiate an interest in the N.I.A.D.D.K. in their helping the American Brittle Bone Society develop audio-visual and print materials that we can disseminate through a chain of volunteers that will be geared to educating young women in their teenage years. I feel that such an educational program sponsored at the secondary school level will be the only way to reach most young people with information of this nature. At last year's National Education Association (NEA) Convention, many educators said they would welcome an osteoporosis prevention program.

Our goal for research is a safe, effective, low-cost way to screen, treat, and evaluate treatment of osteoporosis. Many new techniques have been advanced, but only a few hold promise, and still much work must be done to refine these methods. To date, there is no FDA-approved drug or therapy. (Please see attached letter for some idea of the impact of osteoporosis.)

. . . .

Just when we think we've found an answer, the question changes. This has long been the story of another brittle bone syndrome, rare but more profound in its assault on the body overall. A six-year-old girl in South Jersey who weighed 7lbs., 5oz. at birth now weighs 16 pounds and cannot yet hold her head up. She suffers multiple fractures every few weeks from no trauma that you would ever recognize as tremendous enough to cause a fracture. She breaks an arm, a vertebra, and her pelvis with a sneeze or even just a muscle cramp. This little girl is lying in an Atlantic City Hospital right now with all these fractures and more and her lungs are filling up with fluid because of congestive heart failure that only now has been diagnosed because the physician and staff always assumed it was pneumonia and treated it as such. This is her 15th or so hospitalization for this condition that has gone untreated because the available information had not trickled down to the attending physician. And now little Katie wants to go to sleep. She is so tired. "I don't feel too good, mommy," she says.

Last night, the mother phoned me. Could I help her? Immediately I told her to have her doctor phone a clinical expert on the condition who is in another city but always is available for consultations. The parents are afraid they will upset their doctor who has assured them he has the matter in hand, but I've goaded them into doing what is right for that child.

Education is the role we play in all this, and I am happy to be on call to provide the service, but there is not enough information. The children are still dying. We need help desperately.

There is a growth disorder associated with osteogenesis imperfecta, and heart and lung problems, deafness, and even brittle bones seem to resemble early-onset aging; perhaps there is accelerated aging involved here.

These victims of a heartlessly relentless disorder are aware of all the help they need to function, and they beg you for it. Their intellectual capacity is normal and often well above normal as in my own son's case. He is 8½ and in the intellectually gifted program of the Pennsylvania public school system. He wants to be President of the United States and feels the age requirement should be lowered to 30. He says he'll mark time by being a Representative or Senator.

The FY '83 budget (most recent available. see attachment.) at N.I.H. for funding for osteogenesis imperfecta (O.I.) research was $755,000. Except for an increase to offset the rising cost of doing business, I request only that you maintain this level of funding. It is not nearly enough, but I do recognize the fact that O.I. is a rare disease and is not cost-effective to focus heavily on because so few people would be helped. I am grateful for the boost you have given to elevate this disease to a fundable status. In fact, you have increased funding (not factoring in inflation) for osteogenesis imperfecta by 1,000%!! Thank you.

All I do ask is that you request that all monies be directed at the aging aspects of O.I., particularly the cardio-pulmonary syndrome, and at the growth-deficiency syndrome. And if any can be found, I would hope that aids to weight-bearing and cardio-pulmonary function could be developed and produced, as well as, a safe, comfortable, and appropriate car chair for an adult dwarfed by osteogenesis imperfecta. Cost-effective will never be a word you use around these people, but, oh, how they need your help.

Thank you.

Paul Imbert
2905 Michigan Avenue
Niagara Falls, New York 14305
January 4, 1984

President Roberta DeVito
American Brittle Bone Society
1256 Merrill Drive
Marshalton, Pa. 19380

Dear Mrs. DeVito

I would like your opinion on what can be done for my Mother's condition of osteoporosis.

She has had the disease for about four years. She cannot do ordinary everyday things for fear of breaking the brittle bones of her back. She has previously fractured six bones in her back, however, because of the disease, doctors have told her that her bones did not heal normally, and they sag to form a wedge that pinches the nerves in-between her bones. Doctors have given her estrogen to help her condition, but she cannot use it because it clots her blood flow. I respect the doctors' opinions, however, I don't like dead ends when it comes to a loved ones health, so I am turning to you to see if any research on osteoporosis can be beneficial to my mother.

Writing as someone who cares, I would appreciate your help. First I would like to know if anything can be done, and second, if something can be done, how could we surpass the obstacle of transportation problems that could be involved. Since the bones are brittle, normal transportation is extremely complicated.

Sincerely

Paul Imbert

NIH FY83 SUPPORT IN OSTEOPOROSIS (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5R01AM07912-19		HEANEY, ROBERT P	CREIGHTON UNIVERSITY	$230,922
Longitudinal study of a pre-osteoporosis population (women)				
5R01AM21190-05		SANDLER, RIVKA B	UNIVERSITY OF PITTSBURGH	$190,972
Life styles and bone densities of postmenopausal women				
5R01AM27065-04		RIGGS, B LAWRENCE, JR	MAYO FOUNDATION	$115,167
Epidemiology of bone loss, osteoporosis and fractures (human)				
5R01AM27974-03		BRIGHTON, CARL T	UNIVERSITY OF PENNSYLVANIA	$151,197
Maintenance of quality of aging bone with electricity (rabbit, rat)				
5R01AM28576-03		RIGGS, B LAWRENCE, JR	MAYO FOUNDATION	$230,374
Fluoride and calcium treatment for osteoporosis (human)				
5R01AM28583-03		KLEEREKOPER, MICHAEL	HENRY FORD HOSPITAL	$191,166
Safety and efficacy of fluoride therapy in osteoporosis (human)				
Endosteal bone volume regulation and osteoporosis (rats, mats, birds)				
1R01AM31844-01		JEE, WEBSTER SHEW S	UNIVERSITY OF UTAH	$160,321
Manipulation of bone remodeling in aging (dogs)				
5R01AM22189-05		JOHNSTON, CYRUS C, JR	INDIANA UNIV-PURDUE UNIV AT INDIANAPOLIS	$67,403
Skeletal metabolic abnormalities in diabetes mellitus (human)				
5R01AM27926-03		GENANT, HARRY K	UNIVERSITY OF CALIFORNIA SAN FRANCISCO	$97,582
Vertebral mineral loss in metabolic bone disease (human)				
5R01AM29792-02		GALLAGHER, J CHRISTOPHER	CREIGHTON UNIVERSITY	$59,241
Hormone therapy on postmenopausal bone loss (human)				
1..J1AM32158-01		ARMBRECHT, HARVEY J	ST. LOUIS UNIVERSITY	$29,294
Changes in calcium and vitamin D metabolism with age (rats)				
1R01AM32526-01		HEATH, HUNTER, III	MAYO FOUNDATION	$97,512
Human calcitonin physiology and bone disease				

NIH FY83 SUPPORT IN OSTEOPOROSIS (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
2P01AG00376-09	0003	GUNDBERG, CAREN M	CHILDREN'S HOSPITAL MED CTR (BOSTON)	$46,506
Aging cells and tissues-Osteocalcin and vitamin K metabolism in osteoporosis				
5R01AG00918-06		COHN, STANTON H	ASSOCIATED UNIV-BROOKHAVEN NATL LAB	$198,479
Gerontological changes in skeletal mass (post-menopausal women)				
5R01AG01029-05		SMITH, EVERETT L	UNIVERSITY OF WISCONSIN MADISON	$75,532
Exercise, a modality for bone accretion in the aged (middle aged women				
2R01AG02483-04		WASNICH, RICHARD D	KUAKINI MEDICAL CENTER	$327,928
Epidemiology of osteoporosis in an aging Japanese population				
1R01AG03023-01		MARTIN, R BRUCE	WEST VIRGINIA UNIVERSITY	$102,709
Mechanical stimuli and estrogen in bone remodelling (dogs)				
5R01AG03418-02		NEER, ROBERT M	MASSACHUSETTS GENERAL HOSPITAL	$55,101
Pathophysiology of age-related bone loss (human)				
5R01AG03865-02		BURNELL, JAMES M	UNIVERSITY OF WASHINGTON	$108,646
Osteoporosis--Subtypes and treatment response (human)				
5R23DE06033-02		KRIBBS, PATRICIA J	UNIVERSITY OF WASHINGTON	$43,067
Osteoporosis and oral changes in older women				
5M01RR00030-22	0305	DREZNER, MARC K	DUKE UNIVERSITY	$16,874
General clinical research center Efficacy and safety evaluation of rocalatrol in osteoporosis				
5M01RR00037-23	0300	CHESTNUT, CHARLES H	UNIVERSITY OF WASHINGTON	$23,112
General clinical research center Response of calcitonin to estrogen therapy in postmenopausal osteoporosis (human)				
5M01RR00037-23	0301	CHESTNUT, CHARLES H	UNIVERSITY OF WASHINGTON	$23,112
General clinical research center 25-(OH)2 cholecalciferol as therapy in post memopausal osteoporosis (human)				

NIH FY83 SUPPORT IN OSTEOPOROSIS (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5M01RR00040-23	0233	HADDAD, JOHN G General clinical research center Studies in metabolic bone disease (human)	UNIVERSITY OF PENNSYLVANIA	$11,606
2M01RR00047-23	0248	SCILEPPI, K General clinical research center Lactose intolerance - Correlations with osteoporosis (human)	CORNELL UNIVERSITY MEDICAL CENTER	$24,803
2M01RR00055-22	0283	ROSENBERG, IRWIN H General clinical research center The treatment of steroid-induced osteoporosis (human)	UNIVERSITY OF CHICAGO	$7,276
5M01RR00058-22	0118	KOZIN, FRANKLIN General clinical research center Reflex sympathetic dystrophy in stroke patients	MEDICAL COLLEGE OF WISCONSIN	$13,872
5M01RR00082-21	0187	THOMAS, WILLIAM C General clinical research center Metabolic bone disease (human)	UNIVERSITY OF FLORIDA	$9,851
5M01RR00125-20	0360	LANG, ROBERT General clinical research center-adult and children Transient migratory osteoporosis (human)	YALE UNIVERSITY	$16,128
5M01RR00125-20	0406	RASMUSSEN, HOWARD General clinical research center-adult and children Combined phosphate and calcitonin for postmenopausal osteoporosis	YALE UNIVERSITY	$16,128
5M01RR00211-19	0174	PALMIERI, GENARO M General clinical research center Salmon calcitonin in steroid-induced osteoporosis (human)	UNIVERSITY OF TENN CENTER HEALTH SCIEN	$32,381
5M01RR00334-17	0162	ORWOLL, ERIC S General clinical research center Bone density as a function of aging (human)	OREGON HEALTH SCIENCES UNIVERSITY	$16,158

NIH FY83 SUPPORT IN OSTEOPOROSIS (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5M01RR00334-17 General clinical research center Metabolic bone disease after gastric surgery (human)	0165	ORWOLL, ERIC S	OREGON HEALTH SCIENCES UNIVERSITY	$16,158
5M01RR00585-12 General clinical research center Calcium absorption in health and metabolic bone disease (human)	0064	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00585-12 General clinical research center Fluoride balance studies (human)	0173	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00585-12 General clinical research center Treatment of osteoporosis with 1,25-dihydroxy vitamin D (human)	0174	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00585-12 General clinical research center PTH infusion studies (human)	0211	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00585-12 General clinical research center Fluoride treatment of osteoporosis (human)	0212	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00585-12 General clinical research center Osteoporosis studies (human)	0221	RIGGS, B LAWRENCE	MAYO FOUNDATION	$7,482
5M01RR00633-11 General clinical research center Osteoporosis originating from renal hypercalciuria (human)	0205	PAK, CHARLES Y	UNIVERSITY OF TEXAS HLTH SCI CTR DALLAS	$29,420
5M01RR00633-11 General clinical research center Sodium fluoride use in coherence therapy of osteoporosis (human)	0238	PAK, CHARLES Y	UNIVERSITY OF TEXAS HLTH SCI CTR DALLAS	$29,420

NIH FY83 SUPPORT IN OSTEOPOROSIS (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5M01RR00865-10 General clinical research center Osteoporosis relation with androgens, estrogens and thyroid hormones (human)	0111	JUDD, HOWARD L	UNIVERSITY OF CALIFORNIA LOS ANGELES	$6,778
2M01RR01066-06 MGH general clinical research center Effects of combined hPTH and calcitonin in osteoporosis (human)	0012	SLOVIK, DAVID M	MASSACHUSETTS GENERAL HOSPITAL	$84,810
			TOTAL OSTEOPOROSIS	3,001,898

NIH FY83 SUPPORT IN OSTEOGENESIS IMPERFECTA (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
7R01AM33945-01 Collagen biochemical studies of osteogenesis imperfecta (human)		BURGESON, ROBERT E	MEDICAL RESEARCH FOUNDATION OF OREGON	$82,027
5R01AM30426-02 Type I collagen biosynthesis in osteogenesis imperfecta (human)		ROWE, DAVID W	UNIVERSITY OF CONNECTICUT HEALTH CENTER	$79,913
2R01AM26489-04 Biochemistry and morphology of inborn skeletal diseases (human)		EYRE, DAVID R	CHILDREN'S HOSPITAL MEDICAL CENTER	$91,027
1R01AM31649-01 Proteoglycans in chondrodysplasia		WRIGHT, THOMAS N	UNIVERSITY OF WASHINGTON	$89,477

NIH FY83 SUPPORT IN OSTEOGENESIS IMPERFECTA (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5P01AM16516-13		PROCKOP, DARWIN J	RUTGERS UNIVERSITY MEDICAL SCHOOL	$265,000 1/
Biochemistry of normal and diseased connective tissue				
5K04AM00504-05		FRASCA, PETER	THOMAS JEFFERSON UNIVERSITY	$39,366
Ultrastructure of normal and diseased bone				
1F32AM07171-01		BONADIO, JEFFREY F	UNIVERSITY OF WASHINGTON	$20,040
Molecular mechanisms of type II osteogenesis imperfecta				
5F32AM06913-02		TSIPOURAS, PETROS C	RUTGERS UNIVERSITY MEDICAL SCHOOL	$12,390
Analysis of procollagen genes in osteogenesis imperfecta				
5M01RR00030-23	0159	PINNEL, SHELDON R	DUKE UNIVERSITY	$18,461
General clinical research center-abnormal collagens in connective tissue disease				
5M01RR00069-22	0265	SOLOMONS, CLIVE C	UNIVERSITY OF COLORADO HLTH SCIENCES CTR	$10,726
Pulmonary function in cystic fibrosis-osteogenesis imperfecta				
2M01RR00125-21	0381	GERTNER, JOSEPH M	YALE UNIVERSITY	$16,995
General clinical research center - adult and children-treatment of osteogenesis imperfecta				
5M01RR00425-16	0223	RIMOIN, DAVID L	LOS ANGELES COUNTY HARBOR-UCLA MED CTR	$11,423
General clinical research center-genetics and pathogenesis of osteogenesis imperfecta				

1/ This amount is approximately half of the total grant award reflecting the portion attributed to osteogenesis imperfecta.

NIH FY83 SUPPORT IN OSTEOGENESIS IMPERFECTA (PRIMARY)

PROJECT	SUB	PRINCIPAL INVESTIGATOR	INSTITUTION	AWARD
5M01RR00425-16	0268	HOLLISTER, DAVID W	LOS ANGELES COUNTY HARBOR-UCLA MED CTR	$11,423
General clinical research center-collagen biochemical studies of osteogenesis imperfecta				
5M01RR00722-12	0097	LEVIN, STEFAN	JOHNS HOPKINS UNIVERSITY	$6,972
General clinical research center-heterogeneity in osteogenesis imperfecta				
			TOTAL OSTEOGENESIS IMPERFECTA	755,240

STATEMENT OF DR. JAMES B. FIELD, CHAIRMAN, NATIONAL DIABETES ADVISORY BOARD

PREPARED STATEMENT

Senator WEICKER. Dr. James Field, national chairman of the National Diabetes Advisory Board.

Dr. Field, I am ready.

[The statement follows:]

STATEMENT OF DR. JAMES B. FIELD

I am Dr. James B. Field, Professor of Medicine at Baylor College of Medicine, Houston, Texas and chairman of the National Diabetes Advisory Board, which was established by Congress to review and evaluate the implementation of a long-range diabetes plan and to report annually to Congress and the Secretary of HHS on recommendations for future policies, programs, and budgetary requirements. The Board recently completed its annual report which will be printed and sent to you shortly. The report describes the tremendous progress of the diabetes program during the last few years and the significant opportunities for future advances both in research and its application to treatment. These advances and opportunities, described in greater detail in the recent report of the Board-sponsored Second National Diabetes Research Conference, offer the potential for significant decreases in the tremendous economic burden of the disease and a corresponding increase in the quality of life of individuals with diabetes.

Diabetes is a serious disease. It is the leading cause of adult blindness and accounts for about 25 percent of all cases of kidney failure. Women with diabetes have a 5-7 fold increased risk of heart attack and diabetic men also have an elevated risk of death or disability from this complication of diabetes. Strokes, neurological disorders, amputations, and complications of pregnancy are all more common in persons with diabetes.

Diabetes also is a costly disease. The economic burden associated with this disease is rising due to an increase in the number of people with diabetes and the increasing average age of the U.S. population. A major portion of this economic burden falls directly on the federal government and the taxpayer through the Medicare and Medicaid programs and the direct health care responsibilities of the Veterans Administration (VA), the Indian Health Service (IHS), the Department of Defense (DOD), and other federal agencies. For example:

- The cost of kidney dialysis and transplantation for diabetic patients alone will approach $2 billion per year by the end of this decade. The Medicare-funded End-Stage Renal Disease Program, the Veterans Administration, and the Indian Health Service share the major portion of this economic burden.

- About 20,000 amputations of toes, feet, and legs occur annually in persons with diabetes. This number represents about half of all non-traumatic amputations in this country. The hospital costs alone of these amputations are about $250 million, more than the total federal expenditure for diabetes-related research and control programs. Again, a major share of these expenses are borne by the Medicare/Medicaid program, the Veterans Administration, and the Indian Health Service.
- About 5,000 new cases of diabetes-related blindness occur each year. Federal and state disability payments, benefits, and rehabilitation services alone total approximately $50 million annually.

Based on our current knowledge, diabetes cannot be cured. While the present use of diet, insulin, and other medications is capable of controlling the acute symptoms of the disease, they do not restore normal metabolism of carbohydrate, protein, and fat. This disturbed metabolism leads to the complications of the disease, the shortened life expectancy, and the decreased quality of life. However, a comparison of the Board's latest report with its its first report in 1978 demonstrates that remarkable progress has been achieved through research supported by the National Institutes of Health. The following examples reflect considerable progress toward the ultimate goal of preventing or curing diabetes, reducing the economic burden, and improving the quality of life:

- Production of human insulin by recombinant DNA technology now assures adequate supplies of this essential hormone.
- The demonstration of immunological and genetic factors in the development of insulin-dependent diabetes has expanded the opportunities to develop preventive therapies.
- Successful islet transplantation across major species barriers in animals has brought this potential cure for insulin-dependent diabetes to the threshold of human application. Segmental pancreatic transplantation has successfully restored carbohydrate metabolism to normal in selected diabetic patients.

- Increasing evidence from animal and human studies indicates that meticulous control of blood sugar has a beneficial effect on the chronic, degenerative complications of diabetes.

- The development of insulin pumps now permits the near normalization of blood glucose for prolonged periods of time. While these devices are not ready for general use, they facilitate studies to determine whether the complications of diabetes can be reduced, delayed, or prevented by rigorous control of blood glucose. (Such a study, the Diabetes Control and Complications Trial, has been initiated by the NIADDK. However, funds to continue this important study beyond the current feasibility phase are not available.)

- Studies have demonstrated that strict control of blood glucose levels in pregnant diabetic mothers can normalize fetal insulin secretion and thereby prevent all of the infant morbidity and mortality associated with diabetic pregnancies except for congenital malformations. A current study by the NICHD will determine if strict control of blood glucose in the first trimester of pregnancy can prevent these malformations.

- Clinical studies have established that laser treatments signficantly reduce the risk of blindness from proliferative diabetic retinopathy.

- New pharmacologic agents have been developed that may significantly increase our ability to prevent diabetic retinopathy and neuropathy. These agents are being evaluated in collaborative clinical trials.

- Kidney dialysis and transplant teams in selected centers have demonstrated that mortality and morbidity rates associated with these procedures in diabetic patients need not be different than in non-diabetic patients.

Some of these advances in our understanding of diabetes and its complications can be applied to patients today. In fact, several projects supported by the Centers for Disease Control have already documented significant reductions in diabetes-related hospitalizations following carefully planned diabetes patient education programs that incorporated current medical knowledge about this disease. For example:

- A large-scale patient education program in Maine has documented a net reduction of 32.2 percent in the number of hospital days required for the 813 participating patients. The savings in hospitalization costs were almost three times the cost of the education program. Similar reductions in hospital admissions were documented following patient education programs in Michigan and Rhode Island.

The above example reflects both the tremendously useful information that has already resulted from biomedical research as well as the potential for significant reductions in the economic impact of this disease. However, we cannot rest at this stage of the effort to control diabetes. Most of the recent advances in the prevention, treatment, and control of diabetes are a result of increased federal support during the mid and late 1970s. This impetus has not been maintained in the 1980s, since available funds for these programs have not kept pace with inflation. For example, the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, (NIADDK), the lead institute for diabetes research, has historically funded approximately 45 percent of approved, scientifically meritorious applications. Estimates for fiscal year 1984 show that the award rate will decline to about 27 percent if the Institute does not reduce the current year budgets for previously awarded grants.

This serious decline in research resources would be dramatically compounded by the Administration's proposed budget for fiscal year 1985. This budget would permit a normal award rate of only 11 percent, unless even deeper cuts were made in all ongoing programs. In fact, the Institute would have to cut the budgets of all research centers by 19 percent, competing grants by 15 percent, noncompeting grants by 8 percent, and manpower development programs and intramural research by comparable amounts, just to achieve an award rate of 28 percent under the proposed budget for fiscal year 1985.

In addition to its direct impact upon the diabetes-related research and manpower development programs of this country, the Administration's budget proposal is an ironic example of shortsighted policy, since the increasing economic burden of diabetes directly increases federal expenditures for health care delivery programs, as described earlier.

Recommendations

The Board believes that the advances and opportunities summarized in its report justify a strengthened and expanded diabetes program to (1) seek more basic and fundamental information leading to the prevention and cure of the disease itself, and (2) develop and evaluate improved methods for treating the disabling complications. The Board's recommendations for FY 1985 represent the minimum resources necessary to continue the research programs of NIH at the current level of effort and provide full support to essential activities which have not kept pace with cost increases of recent years.

The Board recommends that Congress provide $550 million in FY 1985 for the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases (NIADDK), including $110 million (an increase of $16.8 million) for diabetes-related activities within NIADDK. This budget will restore full recommended support for approved investigator-initiated research grants; permit funding of competing research grants to the paylines and award rates realized during fiscal years 1977-80; and fully support diabetes centers, research manpower development programs, and other priority activities.

The Board also recommends the following budgets in FY 1985 for diabetes-related activities of the other NIH institutes: NHLBI $20 million (+ $2.2 M), NEI $26 million (+ $3. M), NICHD $11 million (+ $1.6 M), NINCDS $8.5 million (+ $1.2 M), NIAID $7 million (+ $1.1 M), NIA $3 (+ $.5 M), NIDR $2.5 million (+ $.2 M), NIGMS $1.1 million (+ .1 M), NIEHS $.2 million (+ $.1 M), DRR $20.7 million (+ $2.9 M). The increase for DRR is particularly required for the General Clinical Research Centers Program. The vast majority of all clinical investigation related to diabetes is conducted in these facilities. There has been a major decline in the number of centers and beds during the past decade since available funds have not kept pace with inflation.

Dr. FIELD. Mr. Chairman, I am Dr. James Field. I am chairman of the National Diabetes Advisory Board.

I would like to thank you, first of all, for the very inspiring and excellent talk which you gave to a coalition of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases on February 21 at a luncheon meeting. It really was extremely well received.

In the short time that I have I would like to cover four areas. The first area is the economic impact of diabetes in this country. It has been estimated that it is approximately $10 billion per year. Twenty-five percent of all people in instage renal disease in this program are diabetics, and by the end of this decade it will be estimated that the cost of diabetics in such programs will amount to $2 billion annually.

Diabetes is the leading cause of blindness in the adult. Diabetes is responsible for half of the nontraumatic amputations in this country. The hospitalization cost for these nontraumatic amputations among diabetics is $250 million a year, more than twice the amount of money that is appropriated for diabetes research by itself.

Diabetes is also the underlying cause of heart disease in women and men. This cost is borne by the Federal Government through medicare/medicaid, the Veterans Administration, and the Instage Renal Disease Program.

The second area I would like to talk about are the opportunities which exist. The National Diabetes Advisory Board recently sponsored a conference at which over 150 world authorities in the various areas of research in diabetes met and brought up to date the current advances in diabetes and outlined future opportunities.

Ever since the discovery of insulin in 1921, never has the outlook been brighter than it is now. There is evidence in animals and in patients that the regulation of blood sugar can help reduce the $10 billion drain of this disease. There is immunological and genetic information which indicates that we may be able to pinpoint in advance those people who are most susceptible to develop diabetes and perhaps institute preventive programs.

We are able, with very good control of the blood sugar and monitoring the baby, to reduce the fetal complications of the diabetic woman who is pregnant to those in the nondiabetic all except for congenital anomalies which are four times more common in diabetics than nondiabetics, and they are currently doing studies now supported by the National Institutes of Health to see whether meticulous control of the blood sugar before and during the first part of pregnancy when the organs are formed can prevent these congenital malformations.

Eyelids have been transplanted across species barriers in animals.

And I think within 12 months we will see it in humans. There have also been segmental pancreatic transplants in humans which has returned carbohydrate consumption back to normal.

These are just a few of the exciting advances which hold more promise for the diabetic now than ever before. The third area I would like to talk about is the devastating effect of the President's proposed budget.

The National Institute of Diabetes, Arthritis, Digestive and Kidney Diseases, if it is held to the budget which is proposed, would only be able to fund 11 percent of the approved research grant. This is down from the 28 percent which is being funded this year, and the only way they could get the 28 percent this year was to reduce previously awarded and previously funded budgets by study sections.

If the President's budget is put into effect, the only way that the Institute could increase the number of grants funded would be to reduce already approved grants by 8 percent, new grants by 15 percent, center grants by 19 percent, and there would be commensurate reductions in training as well.

So that this is an unacceptably low percent, 11 percent. It is not surprising that young physicians are dissuaded from going into research careers when their futures are uncertain.

The last area I would like to cover is a recommendation that the budget for this Institute be increased over and above what the President asks, to the figure of $550 million, which would include $110 million for diabetes-related research.

There are other more specific recommendations in other institutes, including the General Clinical Research Center which supports 75 to 80 percent of all clinical research in diabetes. Those are in the formal testimony.

Thank you very much.

Senator WEICKER. Thank you very much, Doctor. I appreciate your comments.

STATEMENT OF DR. RICHARD B. FREEMAN, HEAD, NEPHROLOGY UNIT, UNIVERSITY OF ROCHESTER MEDICAL CENTER, IMMEDIATE PAST PRESIDENT, RENAL PHYSICIANS ASSOCIATION

PREPARED STATEMENT

Senator WEICKER. Dr. Richard Freeman, head of the Renal Physicians Association.

Dr. FREEMAN. I am speaking for the Renal Physicians Association, and in that regard I respectfully request, Senator, that the statement of Dr. Robert Schreier, President Elect of the National Kidney Foundation, be entered into the record.

Senator WEICKER. It will be entered into the record in its entirety along with your statement.

[The statement follows:]

STATEMENT OF THE RENAL PHYSICIANS ASSOCIATION

The Renal Physicians Association (RPA) is a national association of academic and practicing physicians that has as its goals enhancement of research in diseases of the kidney, education and quality patient care for patients who suffer from kidney and urologic disorders. The RPA is an active member of the Intersociety Council on kidney and urologic diseases which represents virtually all physicians and scientists active in research and treatment of kidney and urologic disorders. The RPA was involved directly in the development of the intersociety Council's Consensus Statement to Congress. We strongly support the contention that information on the causes of kidney diseases, existing modalities and investigational resources provide a solid base for targeted basic and applied research aimed at the prevention of end stage renal disease (ESRD). The program proposed by the Council and the RPA will reduce significantly the present 2.1 billion dollar expenditure for ESRD over the next decade. The goal of the program outlined in this statement is to reduce the numbers of new patients entering the maintenance dialysis treatment programs to 25% of the 1983 figure by the year 1994. We believe this goal is realistic.

The major causes of ESRD are: immunologic diseases, hypertension, hereditary and environmental factors, diabetes mellitus and acquired disorders of the normal drainage of the urinary tract that lead to progressive destruction of kidney tissue. Basic mechanisms of cellular dysfunction, vascular disease, consequences of toxins, predisposing hereditary characteristics and obstruction of the urinary tract have been identified in research laboratories and require translation to primary or secondary measures of prevention in the population at risk. To this end, the Council and the RPA propose the establishment of multidisciplinary research centers each of which will attack one of the following discrete categorical areas:

- Immunologic diseases of the kidney including emphasis on transplant immunology
- Effect of hypertension on the kidney
- Effect of diabetes on the kidney
- Hereditary and environmental causes of kidney failure, including toxic nephropathy

- Nutrition in the primary and secondary prevention of renal failure
- The cellular basis for disturbances in regulatory and excretory functions of the kidney

The most efficient approach to accomplish this high priority preventive program is to organize two research centers in each category for targeted research in each of the categorical disease areas. The mission of each center will be: 1) To organize basic research aimed at factors which cause renal damage and techniques to eliminate or block their action; 2) Develop and execute appropriate clinical trials; and, 3) Formalize prescriptions for treatment.

Each center must have the following characteristics:

- Multidisciplinary expertise in basic "bench research", clinical research and accessibility to target patient populations. It is assumed therefore that individual centers will involve multiple institutions to insure maximal strength in each of these areas and may include basic science as well as clinical departments.
- A clear recognition that the commitment is total for a minimum of 5 years
- An organizational approach for the integration of the multiple facet investigational approach

The Council and RPA notes that no centers have been previously supported in the kidney-urology area. Further, the amount of general support for kidney and urologic research has neither kept pace with recent inflation nor permitted growth in areas where new discoveries have suggested opportunities for eliminating or reducing causes of ESRD. The Council and RPA recognize that continued strong research support through individual investigator awards is necessary for innovative and fundamental breakthroughs in medical science. Programmatic targeted research, however, using outstanding multidisciplinary resources, are most effective in solving specific well defined problems in biomedical research as well as other disciplines. The Council and the RPA therefore urge a two-pronged thrust in kidney-urology research support: 1) The maintenance of the existing individual investigator award system to encourage innovative and imaginative investigation in basic and clinical studies in the general area of kidney-urology research; and, 2) The implementation of new funding for targeted research to eliminate or reduce the major causes of ESRD.

Examples of the impact of preventive measures through expanded research and clinical application are as follows:

- Hypertension is the most common cause of ESRD in blacks (28% of the ESRD population) and contributes to loss of the kidney function in other types of kidney disease. Hypertension can be controlled.
- Diabetes mellitus accounts for 20% of new ESRD patients. Experimental models of the kidney lesion of diabetes show that the disease is reversible. Kidneys from diseased animals show regression of damage when transplanted from diabetic to normal animals. Diet, control of blood sugar and hypertension delays progression of kidney failure.
- Animals with the genetic predisposition to develop polycystic kidney disease do not develop renal failure when maintained in a germ-free state. Exposure to bacteria triggers the development of cysts that destroy normal tissue. The triggering mechanism needs better definition. Cystic disease is responsible for 10-15% of new ESRD patients.
- Toxic effects of protein, phosphorus and, perhaps, certain lipids accelerate renal failure in all kidney diseases. Progression to end stage renal disease may be prevented or delayed with proper dietary restrictions.
- The most common cause of ESRD is a group of diseases categorized as glomerulonephritis. Most are due to destruction of tissue by immunologic mechanisms - antibodies or "killer" lymphocytes. New drugs that suppress antibody formation to kidney tissue or limit lymphocyte production reverse disease in certain types of nephritis. Monoclonal antibodies are effective in diseases similar to nephritis.

The Council and RPA note the analysis and recommendations of the Coalition for Support for Funding of the National Institutes of Arthritis, Diabetes and Digestive and Kidney Diseases. The Council and RPA support its recommendation of 550 million dollars for fiscal year 1985, with a target of 37% of approved individual grants funded with a minimum priority score of 190 as a basic requirement to sustain the current individual investigator award program. The

Council and RPA submit, however, that the tremendous federal outlay for ESRD treatments will continue to increase unless kidney research receives additional support to mount an aggressive coordinated effort to formalize preventive measures. This has not, and is not, being done in a comprehensive drive. The Council and RPA proposal will meet this need and will reduce health care expenditures for the treatment of ESRD.

As a realistic timetable, it is proposed that six centers, one in each category, be established in fiscal year 1985; three additional centers in 1986, with the total number of centers reaching twelve in 1987. The Council and RPA recommend an add on to the NIH appropriations of 6 million dollars for the 1985 NIADDK budget, 9 million dollars for 1986 and 12 million dollars for 1987. This schema will permit a stepwise development of twelve centers for coordinated investigational attack on the problem of ESRD by 1987.

In summary, this analysis performed by experts representing all disciplines in the field of kidney and urologic diseases reveals a void in deliberate prospective research and demonstrations in primary and secondary prevention of chronic kidney failure. This deficiency persists at a time when major advances in the understanding of causes of disease and factors influencing progression of disease are at hand. The Council and RPA submit that this area deserves the highest priority and is the only reasonable approach to decrease the projected federal expenditures for the treatment of kidney failure over the next decade. The proposed add on allocation plus continued support of existing research and development in the kidney-urology area still amounts to less than one half of one percent of the total federal outlay for the treatment of ESRD.

Dr. FREEMAN. A combined drive on renal disease is now possible. We feel that this would reduce the numbers of end stage renal disease patients by 75 percent. We feel this is a realistic goal in 1994.

Examples of how this can be done are as follows:

Hypertension is one of the leading factors in 22 percent of all patients and 43 percent of the blacks. Hypertension can be controlled.

Diabetes, as you just heard, is the cause of kidney failure in 50 percent of insulin required diabetics, kidney damage from diabetes results when kidneys are transplanted from diabetic animals into normal animals. Therefore, the damage is reversible.

Diabetics account for 22 percent of all end stage renal disease, according to a recent working paper by Paul Hagers.

Glomerulonephritis is the cause of end stage renal disease in 20 percent of the patients requiring dialysis or transplantation. We are aware that new drugs and treatments are available to control disorders of the immune system and this is an area that can be attacked effectively.

The Unit Society Council and the RPA, urge Congress to provide the means to establish multidisciplinary centers of basic and applied research to formalize prospective studies and treatment protocol to prevent end stage renal disease.

We feel that now is the time to start. We suggest the following six areas for attack: hypertension and the kidney, diabetes and the kidney, immunologic disorders, including transplant immunology, toxic, environmental, genetic causes, nutritional factors, and cellular mechanisms of disease.

The Intersociety Council and RPA have detailed the potential structures of these centers which would include neurologist, nephrologists, and transplant surgeons, and it is in our written statement.

We suggest that two centers in each category be established prior to 1987 under the Kidney Program of the NIADDK.

We concur with the statement of the coalition for the funding of the NIADDK which calls for a minimum budget of $550 million. This is to sustain individual investigator awards which are necessary for innovative, fundamental breakthroughs in our understanding of the disease.

However, programmatic, targeted research is the most effective way in solving well-defined problems in the biomedical research area. Thus, we suggest an add-on to the NIADDK budget for kidney urology of a minimum of $6 million to establish at least six centers this year and up to a total of $12 million, by 1987, so that 12 such centers can be created. These centers need not necessarily be located in a single institution but can cover multicenters.

We contend that prevention is the only ethical and medically acceptable means of solving the $2 billion plus End Stage Renal Disease Program.

The 12 major national scientific societies that have supported this document urge Congress to provide the add-on suggestion, which will amount to less than one-half of 1 percent of the present yearly Federal outlay for the treatment of ESRD.

Thank you, Senator.

Senator WEICKER. Thank you very much, Doctor. I appreciate this.

STATEMENT OF ROBERT HUMPHREYS, ESQ., WASHINGTON COUNSEL, ARTHRITIS FOUNDATION

PREPARED STATEMENT

Senator WEICKER. Robert Humphreys, Washington counsel of Arthritis Foundation.

Mr. HUMPHREYS. Mr. Chairman.

Senator WEICKER. Mr. Humphreys.

Mr. HUMPHREYS. Thank you very much for the opportunity to appear. In the interest of conserving the committee's time, I will summarize my statement and ask that it be included in the record.

Senator WEICKER. So included.

[The statement follows:]

STATEMENT OF ROBERT HUMPHREYS

Introduction

Mr. Chairman and Members of the Committee, I am Robert Humphreys, Washington Counsel for the Arthritis Foundation. I appreciate the opportunity to testify on behalf of the Foundation and its professional sections, the American Rheumatism Association and the Arthritis Health Professions Association, and the American Juvenile Arthritis Organization which is a membership component of the Foundation, with respect to fiscal year 1985 funding for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, particularly as it relates to the arthritis research program of that institute.

The Arthritis Foundation is a national voluntary health agency, with 71 chapters and divisions, serving the Nation's 37 million arthritis victims through its 400,000 volunteers. The Arthritis Foundation is the only such agency seeking solutions, through research, education, and patient services, to the myriad problems caused by more than 100 forms of arthritis.

The conventional belief that arthritis is an "old folks' disease" is myth. Although many older persons have arthritis, rheumatic diseases have no regard for age, sex or race. Nor is arthritis merely a collection of minor aches and pains, as the commercials often say. Some forms of rheumatic disease are potentially life-threatening, such as lupus, scleroderma, and some juvenile arthritides. Other are progressively disabling, as in the case of rheumatoid arthritis and ankylosing spondylitis.

Mr. Chairman, we are deeply concerned by the Administration's decision to request only a 2.8 percent increase in the appropriations of the National Institutes of Health. This decision adversely affects the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases to an even greater extent than other NIH research institutes.

We are also disturbed that the directives imposed on NIH by this Committee and the counterpart House Appropriations Subcommittee with respect to arthritis research have not been followed.

Detailed Discussion

Last year this Committee, in its Report on FY 1984 appropriations, called on NIADDK to "significantly expand its research program" on arthritis and musculoskeletal diseases. The House Report contained similar language.

Although NIH administrators did not totally ignore this important legislative history, its actions with respect to the allocation of funds for the Arthritis Division cannot be considered in any measure responsive to the Congress' instruction to strengthen the arthritis research program. Only $700,000 in funding above the across the board "formula" for all divisions was provided to the Arthritis Division in answer to congressional directives to strengthen and expand arthritis research.

Mr. Chairman, the Arthritis Foundation had hoped that the House and Senate report language would result in actions by NIH that would begin to address the inadequate attention to arthritis research that has characterized the program for so many years. We have urged the Department of Health and Human Services to adopt a policy which allocates biomedical research funds on the basis of the magnitude of health problems nationally and the potential for scientific advancement. The table appended to this statement graphically portrays the woeful inadequacy of support for arthritis research as compared with other chronic disease areas. While we cannot gainsay the attention given to research on cancer and other serious diseases, we continue to urge the Congress and the Department to consider the size and complexity of the arthritis problems in our country, and its monumental cost, in both human and economic terms. Consider, for example, these facts:

- 37 million Americans have arthritis, and the number is increasing by a million each year.
- Arthritis disables more people than any other disease or condition: 7 million in the U.S.
- The cost of arthritis, just in terms of lost wages and medical care, is over $13 billion annually.

- There are over 100 separate and distinct forms of arthritis, each with its own symptoms, etiology, and treatment.

- 40 percent of Americans over 65 have arthritis, and with the graying of America, this problem will steadily increase.

- By the year 2000, arthritis and musculoskeletal diseases will cost the nation nearly $100 billion annually.

Despite the lack of support for research in arthritis, great progress has been made during the last decade, and there is strong hope that our knowledge will grow exponentially, leading to improved treatment, cures, and even prevention of arthritis. There is a great danger, however, that the dampening of the biomedical research effort caused by curtailed appropriations will drive talented scientists away from careers in this field, and our current progress will atrophy. As this Committee knows, medical science is largely dependent upon NIH funding. Constantly deteriorating pay lines and award rates endanger the future of this science, and America's preeminence in it.

Spokespersons for other organizations concerned about NIAADK research will address the fact that the number of new grants in this institute would be reduced by 100 under the President's budget, that new grant amounts will have to be reduced by 15 percent, that center funding is to be cut by 19 percent. Smaller grants and fewer grants mean less research and reduced opportunity for scientific advancement. A coalition of more than 40 organizations agree that a minimum funding level of $550 million for NIADDK is necessary to maintain the institute's program at the FY 1984 level. With the Committee's permission, I am providing a copy of the coalition's statement for insertion in the hearing record.

Beyond our endorsement of the minimum appropriation recommended by the coalition for NIADDK as a whole, however, the Arthritis Foundation urges the Committee to examine closely the history of allocations to the Arthritis, Musculoskeletal and Skin Division. The institute provides funds to each of the four divisions on the basis of historical allocations. Regardless of need, or the magnitude of the health problems, or the complexities of disease entities, each division gets the same treatment, in terms of percentage of increase or decrease, as every other division. Thus , there is no room for altered priorities and changing research needs. In absolute dollar terms, the bigger the division's appropriation in prior years, the larger the amount of total dollar increases. The Appropriations Committees should help break this cycle and assign support according to research needs, potential for scientific advancement, the magnitude of the health problem, including economic impact, and the complexities of the diseases.

The Arthritis Foundation urges this Committee to give close scrutiny to the appropriation level it recommends for the Arthritis Division for FY 1985. If the Committee continues to avoid earmarking of funds within NIH, as it generally has in recent years, we ask that you adopt strong and unequivocal report language directing NIH to assign higher priority to arthritis research. The following dollar level recommendations reflect the need for research and the current ability of the arthritis research community to undertake quality scientific investigation. These amounts represent a consensus of a number of prominent researchers in the field. We understand that the National Arthritis Advisory Board will recommend similar levels of support.

For investigator initiated grants (RO-1) we urge an appropriation of $84 million for FY 1985, compared with the current amount, $62.8 million. We believe the Multipurpose Arthritis Centers have been severely neglected over the past several years. Accordingly, we recommend an increase in the number of Centers and increases in center grant award levels, for a total of $14.5 million. These centers are making major contributions to basic research, clinical research, education, and community outreach and service coordination.

Training needs are particularly acute. The strength of the underpinnings of future arthritis research depend to a great extent on the level and quality of National Research Service Awards, Research Career Development Awards, and Clinical Investigator Awards. In addition, data systems research, scientific workshops, conferences, and seminars are essential to the interchange of knowledge and advancement of research. For all these training program areas we recommend funding at $10.8 million.

The infrastructure of research is in need of repair and improvement. A total of $11.5 million is necessary for modernization of equipment and facilities, epidemiology, continuation of the data system, the Arthritis Information Clearinghouse, and R&D contracts. Finally, intramural research in this area is in need of expansion. We recommend $8.5 million for this purpose in FY 1985, compared with the current $7.0 million amount.

Mr. Chairman, the total amount we urge to to be allocated to the Arthritis Division is $129.4 million, exclusive of program management and administration costs. Although this amount is, in relative terms, substantially higher than the amount provided through NIADDK in FY 1984, it is nonetheless quite modest in relation to the potential long term benefit. The widespread alleviation of pain and suffering that would result from increased research efforts would be enormous. The investment of increased funds for arthritis research would be repaid many times over through lower job absenteeism, reduction in the need for attendant care, home health care, institutionalization, hospitalization and other medical expenses, reduced workers compensation payments, and other income maintenance such as Social Security Disability.

In conclusion, Mr. Chairman, the Arthritis Foundation urges this Committee to begin to break the cycle of indifference to one of our nation's major health problems by providing a reasonable level of funding for arthritis research in FY 1985.

1982 RESEARCH FUNDING BY THE FEDERAL GOVERNMENT

DISEASE CATEGORY	EXPENDITURES BY THE NATIONAL INSTITUTES OF HEALTH (NIH)	NUMBER OF PEOPLE AFFECTED	DOLLARS SPENT PER PATIENT
CANCER	$935.3 MILLION	5.0 MILLION*	$187.06
HEART	$322.8 MILLION	35.0 MILLION**	$ 9.22
DIABETES	$ 74.5 MILLION	11.0 MILLION	$ 6.77
LUNG	$ 79.9 MILLION	15.2 MILLION***	$ 5.25
ARTHRITIS	$ 44.8 MILLION	36.0 MILLION	$ 1.24

* American Cancer Society estimate
** National Heart Lung and Blood Institute estimate for all cardiovascular disease
*** National Heart Lung and Blood Institute estimate for bronchitis, asthma and emphysema

1982 PUBLIC SUPPORT

ORGANIZATION	TOTAL PUBLIC SUPPORT*	NUMBER OF PEOPLE AFFECTED	DOLLARS RAISED PER PATIENT
MUSCULAR DYSTROPHY ASSOCIATION	$ 74.7 MILLION	200,000**	$373.50
UNITED CEREBRAL PALSY	$ 32.3 MILLION	700,000	$ 46.14
AMERICAN CANCER SOCIETY	$183.0 MILLION	5.0 MILLION***	$ 36.60
AMERICAN HEART ASSOCIATION	$108.9 MILLION	4.6 MILLION****	$ 23.67
AMERICAN DIABETES ASSOCIATION	$ 20.3 MILLION	11.0 MILLION	$ 1.85
ARTHRITIS FOUNDATION	$ 24.5 MILLION	36.0 MILLION	$ 0.68

* "Total Public Support" is defined as all private contributions including bequests

** Number of people with MD and related dystrophies

*** This figure includes 3 million people cured of cancer and 2 million with active disease

**** Number of people with coronary heart disease

ARTHRITIS FOUNDATION
BUDGET RECOMMENDATIONS FOR FY 1985
ARTHRITIS DIVISION NIADDK
(in thousands of dollars)

Research grants	84,030
Multipurpose Arthritis Centers	14,470
Training*	10,835
NIH intramural research	8,530
Other needs**	11,546
TOTAL	129,405***

* Includes National Research Service Awards, Research Career Development Awards, Clinical Investigator Awards, data systems research, scientific workshops, conferences and seminars.

** Includes modernization of equipment and facilities for extramural research, epidemiology, data system, R & D contracts, and Arthritis Information Clearinghouse.

*** Total is for program costs only and does not include program management and administration.

Mr. HUMPHREYS. Mr. Chairman, I am council for the National Council on Arthritis and just want to present to you a few brief facts to increase attention to arthritis research within the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases.

There are 37 million people with arthritis. Although it is typically thought of as an old people's disease, it is much, much more than that. Sixteen million people have osteoarthritis; 7 million have rheumatoid arthritis.

Some billion dollars a year is spent on quackery, quack cures and unproven remedies, which is many, many times the amount spent on research.

It is projected that by the turn of the century the cost of arthritis to the country will be something in the order of $100 billion in terms of lost economic opportunity, lost wages, lost medical care, lost taxes, and second and third care economic effect of arthritis.

Arthritis research has perpetually been underfunded. In 1982, for example, the estimate was that roughly $1.25 was spent for each arthritis patient on research efforts compared to $187 for cancer research.

We would ask, Mr. Chairman, that the cycle of—although it is not indifference, I expect, but lack of attention, certainly to the needs of 37 million Americans—be turned around and that an increase in the Congress' and NIH's attention to this multifaceted problem be increased.

I will at this point conclude, Mr. Chairman, by saying that an increase and acceleration of the effort on behalf of arthritis victims across the country will result in a vast increase in productivity among the population, a reduction in attendant care, reduction in Social Security disability and medicare costs, medicaid costs—just a panoply of cost reductions that research will ultimately bring to the economic benefit of the country and to the human benefit of the people involved.

Thank you, sir.

Senator WEICKER. Thank you very much, Mr. Humphreys. I appreciate it.

STATEMENT OF DR. RONALD W. LAMONT-HAVERS, NATIONAL ARTHRITIS ADVISORY BOARD

PREPARED STATEMENT

Senator WEICKER. Dr. Ronald Lamont-Havers, vice chairman of the National Arthritis Advisory Board. We will insert your statement in the record.

[The statement follows:]

STATEMENT OF DR. RONALD W. LAMONT-HAVERS

Mr. Chairman and members of the subcommittee, I am Dr. R. W. Lamont-Havers testifying today as vice-chairman of the National Arthritis Advisory Board in support of the FY85 budget of the Division of Arthritis, Musculoskeletal, and Skin Diseases of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, particularly as it affects the need to continue to fight to overcome arthritis.

The National Arthritis Advisory Board was established by P.L. 94-562 in October of 1976, and the authorization was renewed by Congress in 1980 and administratively extended by the Secretary of HHS in September 1983. It had been formed as the result of recommendations in the Arthritis Plan developed by the National Commission on Arthritis and Related Musculoskeletal Diseases in April 1976. This Plan contained an analysis of major areas such as research, education and training, data systems and epidemiology, arthritis centers, and community programs. The principal functions of the Board are to review and evaluate the effectiveness of the Arthritis Plan, to amend it where appropriate, and to submit annual reports to Congress on its activities.

Approximately 1 year ago, in submitting its fiscal recommendations for FY84 in its 1983 Annual Report, the Board presented a reasoned and well-documented appraisal of the needs of those programs, institutions, and personnel engaged in the struggle against arthritic diseases. Our 1983 Annual Report, which was sent to Congress in May 1983, contained a detailed justification of the Board's recommendations. The Board recognizes that fiscal constraints must be imposed and that Congress must allocate the Nation's fiscal assets in a prudent and resourceful manner. However, since many of the Board's FY84 recommendations have not been met, the Board wishes to reemphasize its statements and justifications of last year, which, we believe, are still very valid, and to use last year's recommendations as the basis for this year's. Therefore, in arriving at the dollar figures for FY85 that I will present in a moment, the Board took last year's recommendations into account and increased the dollar amounts based on the anticipated Consumer Price Index and the inflation for biomedical research.

BUDGET RECOMMENDATIONS FOR FISCAL YEAR 1985
NIADDK DIVISION OF ARTHRITIS, MUSCULOSKELETAL, AND SKIN DISEASES
(Thousands of Dollars)

Research Grants	$84,030
Multipurpose Arthritis Centers	16,600
Research and Development Contracts	3,890
Modernization of Equipment and Facilities for Extramural Arthritis Research	4,280
NIH Intramural Research	8,530
Research Career Development Awards, Clinical Investigator Awards, Data Systems Research, Scientific Workshops	4,185
National Research Service Awards (Training)	5,056
Small Business Innovative Research Grants	1,000
Physician-Scientist Awards	500
Epidemiology	2,140
Data	1,020*
Education and Training, Conferences, Seminars and Workshops	963
Arthritis Information Clearinghouse	214†

*Not included in recommendation for research grants.
†In addition to $200,000 currently included in research and development contracts recommendations.

Two new items are highlighted in this year's presentation, since they were not presented last year. The first of these is the Physician-Scientist Awards, which is an innovative program initiated by NIH in FY84 and implemented by NIADDK. This program seeks to meet the great problem of assuring that physicians seeking careers in biomedical research can receive the necessary commitment of support in a critical period of their training.

The second item is support for the Small Business Innovative Research Grants. This NIH program, mandated by Congress, must be considered in any budget plan if further drain on the investigator-initiated research grant program is not to occur.

The amounts recommended for the Physician-Scientist Awards and for the Small Business Innovative Research Grants are approximately that which the Arthritis Division plans to use in FY85.

At this time, I want to express the Board's great concern at the OMB-imposed ceiling of 5,000 investigator-initiated research grants (RO1's) for all of NIH. The Delegation of Basic Biomedical Research had recommended a floor of approximately 5,000 research grants to achieve a level of funding stability for the biomedical research community. The arbitrary requirement that 5,000 grants be a maximum, rather than a minimum level, will result in an overall decrease in the number of NIADDK grants (729 in FY84, 650 or less in FY85).

Even so, in order to meet this mandated lessened number of grant awards, the Administration's budget will require NIADDK to reduce the study section recommended level of support by 8 percent in the case of noncompeting grants, 15 percent in competing grants, and 20 percent in center grants. These types of maneuvers and manipulations only further exacerbate a great anxiety and uncertainty in the biomedical research community. This uncertainty not only increases the problem of keeping effective, productive teams of researchers together, but has a great negative effect on those bright young minds so desperately needed by the Nation's research effort. This is especially unfortunate at this time when exciting arthritis research advances are being reported.

The Board wishes to emphasize its concern over the deleterious effect resulting from any decrease in arthritis research support. It is anticipated that imposition of a maximum figure of 5,000 investigator-initiated research grants for the NIH community will have a disproportionately negative effect on arthritis research.

The Board strongly supports continued funding for Multipurpose Arthritis Centers (MAC's) during FY85. We wish to commend the stand taken by Congress last year that enabled these centers to continue their effective programs.

As last year, the Board believes that funding for Specialized Centers of Research (SCOR's) will supplement the rigorous and successful programs that have evolved under the MAC concept. The Board believes that SCOR's will provide a mechanism for the funding of new programs in the field of arthritis, and that this funding should be in addition to an increase in MAC funding, not a substitute for MAC funding. The approximately $2 million for the SCOR initiative is included in the recommendation for the MAC's. The Board strongly recommends that NIH continue its commitment to support MAC's.

Significant biomedical research opportunities are available in the arthritis field, including (but not limited to) the following areas:

- Research into the molecular biology of immunologic mechanisms identified in such diseases as rheumatoid arthritis, systemic lupus erythematosus, and scleroderma. The basic science technologies are now available to examine the structure and function of antigens found in the serum of patients with several of the major forms of rheumatic disease.
- Biochemical investigation of the structure and metabolism of articular cartilage. Basic information is now available on the chemical composition of cartilage that enables the pursuit of new therapies pertinent to the most common rheumatic disease, osteoarthritis. Over 20 million people are afflicted with this disorder.
- Research into health systems and health care delivery for patients with rheumatic diseases. Members of the arthritis investigative community possess special skills to pursue problems in health systems research. These problems merit further intense investigation parallel to the pursuit of basic research.

These proposals expand the concept and the mandate for arthritis centers. The Board believes that a broader mission for MAC's and SCOR's will accelerate progress toward improved treatment and care of patients afflicted with arthritis and related musculoskeletal diseases. By broadening the mission of the centers, the recommended funding becomes a minimum figure to be considered for FY85.

The Board further recommends an increase in FY85 over the funding levels proposed in FY84 for education and training and for the Arthritis Information Clearinghouse.

For community programs and rehabilitation, the Board makes the following recommendations:

- NIH should increase its funding for MAC's to promote research into the efficacy of modalities used in patient care as part of the NIH commitment to fund applied research.

- NIH, through the MAC's, should support additional research in community rehabilitation, as part of its commitment to use these centers to foster applied research as an expansion of the research goals of NIH.
- The Rehabilitation Services Administration should be encouraged to replicate workplace rehabilitation studies such as those successfully completed in Arizona and North Carolina so that if continued success is found, these innovations can become part of general practice.

In education and training, high priorities include:

- Funding for the Arthritis Information Clearinghouse to continue its important work of collecting and disseminating information and to support regional workshops for health professionals on patient education in arthritis.
- Demonstration projects in arthritis patient education carried out through the MAC's to test state-of-the-art educational programs.
- A research base for patient education in physical and occupational modalities. especially areas such as osteoarthritis and low back pain.
- Studies in patient and family education for children with arthritis to collect and analyze data on how children learn best about their disease at different age levels and different stages and severity of the disease.
- Research in psychosocial aspects of rheumatic diseases to help develop more effective therapeutic methods.

In short, Mr. Chairman and members of the subcommittee, the National Arthritis Advisory Board feels that the Administration's Budget for FY85 is not just a hold-level proposal, but one which will seriously decrease the research effort in overcoming arthritis and related diseases and will continue to erode the Nation's capacity in these areas. The recommendations proposed by the NAAB are mindful of the fiscal realities of today, but seek to to maintain the base of excellence for the future.

Dr. Lamont-Havers. Mr. Chairman, I am going to testify this morning on behalf of the National Arthritis Advisory Board, but first of all, I would really like to highlight and summarize my testimony.

But, first, I would like to echo Dr. Field's appreciation of your address before the NIADDK coalition. It is, indeed, very inspiring.

The suggestions that we are submitting this year for the Arthritis Advisory Board for the fiscal year 1985 budget of the Division of Arthritis, Musculoskeletal, and Skin Diseases of the NIADDK is really based on our testimony of last year, since little was changed with regard to our analysis at that time.

What we have done is to adjust it for the anticipated increase in the cost of living, the biomedical increase. That is outlined in the testimony, Mr. Chairman.

I would, however, like to point out that we are highlighting this year two items which were not addressed last year.

One of them is the physician scientist award, which is an innovative program initiated by NIH this year and implemented by the NIADDK, one of only two institutes that have done so, and this program seeks to meet the great problem of assuring the physicians seeking careers in biomedical research can receive the necessary commitment in the critical period of their training.

The second item is support of small business innovative research grants, and this program, mandated by Congress, must be considered in any budget plan if further drain on the investigative initiative Research Grant Program is not to occur.

I might add that the amounts recommended for both of these programs for fiscal year 1985 is approximately that which the Arthritis Division plans to use. I did feel, however, that this should be highlighted at this time.

I would, however, like to express the board's great concern at the OMB-imposed ceiling of 5,000 investigator-initiated research grants for all of NIH, and I realize, Mr. Chairman, that the delegation of basic biomedical research has spoken before you and that, as you know, they had recommended a floor of approximately 5,000 grants to achieve a level of funding stability in the biomedical research community.

The arbitrary requirement that 5,000 grants be the maximum rather than the minimum will result in the overall decrease in the number of grants made by NIADDK. Even so, that there are a decreased number of grants, the administration's budget would require the Institute to reduce the study section recommended level of support by 8 percent, in the case of noncompeting grants 15 percent, and competing grants at 19 to 20 percent, and incentive grants.

These types of maneuvers and manipulations only further exacerbate great anxiety and uncertainty in the biomedical research community. This uncertainty not only increases the problem of keeping effective, productive means of research together, but has a great negative effect on the bright young minds that are needed by the Nation's medical research effort.

This is especially unfortunate, at this time, when exciting arthritis advances are being reported. Now, I have to deal with this every day, Mr. Chairman, where I am, and I might add, Mr. Chairman, that your committee and Congress has been given the arthritis advisory committe's report which summarizes the great advances that have been made in the last 10 years and what can happen in the future.

I think that the testimony from just within the last 3 years we have come to realize that that is a result of the genetic abnormality in the tissue in which the genes knock out some amino acids. This has great implications, while these individuals are relatively few, there are many, many individuals within society that have a modification of this, and I think, therefore, that the future for arthritis research is great.

There is great problem in the future with the administration's budget. Thank you very much.

Senator WEICKER. Thank you, Doctor. I appreciate it.

The next witness is Barbara Mátia. Welcome, Barbara. You can go right ahead.

STATEMENT OF BARBARA A. MATIA, OF SCOTTSDALE, AZ

Ms. MATIA. Mr. Chairman, it would be impossible for you to know how much it means to come before this subcommittee today, for 7 years ago I was bedridden and asleep 16 hours a day, suffering from rheumatoid arthritis.

Imagine—being bedridden in the prime of your life, and being told by the medical community that there was no known cure for arthritis and, although they would give you the best treatment they had, it would be a slow process of deterioration.

All I could think of at this point was my aunt who had rheumatoid arthritis all her life, who is now crippled, deformed and unable to function normally after having the standard treatment of gold and cortisone.

I learned of a program in Arlington, VA, developed by Dr. Thomas Brown, that was aimed at an infectious organism as the cause of the disease and I decided that I had nothing to lose by trying it.

The first time I met with Dr. Brown in the hospital, he explained that he would use antiinflammatories and liquid antibiotics, such as tetracycline, given intravenously in low dosages, and that there were no harmful side effects from his program.

During that initial visit, Dr. Brown told me it would take 2 years to turn the corner and perhaps as long as 5 years to return to a full and active life. As you can tell by seeing me today, I am totally functional and this devastating disease has been reversed.

When I learned that Dr. Brown testified in Congress, I decided it was time for me to find out why a program which has helped over 10,000 sufferers from arthritis was not being accepted by the Nation's medical establishment. I now think I know the answer to that question and I would like to tell you about it because it is something that Congress can do something about.

One of the first things that I did was to go see Dr. Shulman and Dr. Salans of NIADDK, where I learned that there were four research projects presently underway on the mycoplasma organism and its possible link to arthritis. But I also learned that there are no clinical trials presently underway and that there have not been any since the Boston study in 1971.

I began to realize that the real problem blocking the antibiotic treatment approach was that the Boston study failed.

The 1971 Boston study was a double-blind test of the effectiveness of tetracycline on rheumatoid arthritis in only 13 patients, was conducted for only 1 year, the patients were given oral antibiotics instead of intravenous antibiotics, and no effort was made to make certain all patients were taking some antiinflammatory. The study showed no significant positive effect from the tetracycline. If you have come through Dr. Brown's treatment program, you know why the Boston study failed—because the antibiotics were not given intravenously and because the study ended before the significant results are generally seen. I know how my 5-year recovery process would have measured up in a 1-year study.

Because of the negative results from this test, the medical establishment has, in my opinion, closed its mind to the antibiotic treatment approach.

I consider this to be a national tragedy—that 37 million arthritics may have to wait years for a treatment program which is presently available.

On or before June 1, 1984, Dr. Brown will be submitting an application for an NIH grant to conduct a clinical trial of the Antibiotic Treatment Program he has developed. It is essential that the policymakers, including Congress, become involved in the consideration of this grant application.

After hundreds of millions of dollars have been spent on arthritis research, the Nation's arthritics still have no reason for hope. I have known what it is like to live without hope. I know what it is like to be given hope. And I know what it is like to have a disease reversed and to be able to live a full life again. If a clinical trial of this method of treatment is undertaken, I truly believe the suffering of millions of arthritics will come to an end because they will have the treatment program they deserve.

Thank you very much.

Senator WEICKER. Thank you very much, Barbara.

I wonder, while he is still in the audience, if I might ask for a comment by Dr. Lamont-Havers—of this treatment that Barbara referred to—from a professional's point of view. And I realize I kind of put you on the spot. I don't mean to do that, but I'm just not qualified to evaluate and I wonder if you might help me in that regard?

Dr. LAMONT-HAVERS. This form of therapy, Mr. Chairman, has been considered by the rheumatology and arthritis committee since 1952, when I was a fellow at the Presbyterian Hospital which is when this began to come in. So, there have been a number of attempts over the years. It is an extremely controversial area, and the board did come out with the phrase—I feel very accurate report last year, and I would be very happy to make a copy of that available to you.

I think that as we look into this further, the question comes up as to whether the trial of the therapy whether a trial of mycoplasma to see if an infectious agent is found at this time. Such a trial, to be done properly and, therefore, be of some value, would cost somewhere between at least $2 and $3 million. It is extremely complex.

If you are going to do that you should begin to look at other forms of meteorological agents, not just mycoplasmas. Mycoplasmas are very difficult to work with. At that point you come into some very ethical issues as to whether you want to continue. I think I would also be very happy to make available to you the considerations of the NIADDK itself as to what it would take to undertake such a trial. Not only trial of therapy but also to look at the immunological agents.

I think that it is our opinion at the present that that is not the correct way to spend that amount of money. If you get $2 or $3 million to use on that then it could be used otherwise in the Institute. As you know, if you go back in the literature far enough, meteological agents have risen for arthritis and I think the latest was just 6 weeks ago. But I think (*a*) it is very controversial; (*b*) there is no clear answer; (*c*) it is not as easy to obtain a definitive result.

Senator WEICKER. Barbara, as you can see, you have already raised questions, which is the first step.

I myself am fascinated by your testimony and I will certainly consult with my friends, also, at NIH, so it was well worth your time to come in here. I am learning also from you and, also, from Dr. Lamont-Havers.

Ms. MATIA. I would like to say one thing. I think it is time that some consideration be given to arthritis sufferers of this country.

I find it fascinating that people from all over the world have flown to Washington to be with this doctor. And as I met with patients in the hospital, all of us were at a dead-end point, we felt we had nothing to lose by trying this treatment. I have seen patients who were in wheelchairs, patients who were bedridden, and 5 years later leading active normal lives—children, teenagers, college students, and the elderly.

And I think it is time we give consideration to a longer trial, that is, 6 months to 1 year trial. And I really think serious consideration should be given to this method of treatment, because it is fascinating that we have all had a reversal.

PREPARED STATEMENT

Senator WEICKER. It will be. And, No. 1, you look great. So whatever was wrong with you has been taken care of, and I can assure you, that we will take a long careful look at it.

[The statement follows:]

STATEMENT OF BARBARA A. MATIA

I am Barbara Matia of Scottsdale, AZ.

It would be impossible for you to know how much it means to me to come before this subcommittee today, for 7 years ago I was bedridden and asleep 16 hours a day, suffering from rheumatoid arthritis.

Imagine—being bedridden in the prime of your life, and being told by the medical community that there was no known cure for arthritis and that you would have to adjust to the fact that although they would give you the best treatment they had, it would be a slow process of deterioration.

All I could think of at this point was my aunt who has had rheumatoid arthritis all her life, who is now crippled, deformed, and unable to function normally after having the standard treatment of gold and cortisone.

I learned of a program in Arlington, VA, developed by Dr. Thomas Brown, that was aimed at an infectious organism as the cause of the disease and I decided that I had nothing to lose by trying it.

The first time I met with Dr. Brown in the hospital, he explained that he would use antiinflammatories and liquid antibiotics, such as tetracycline, given intravenously in low dosages, and that there were no harmful side effects from his program.

During that initial visit, Dr. Brown told me it would take 2 years to turn the corner and perhaps as long as 5 years to return to a full and active life. As you can tell by seeing me today, I am totally functional and this devastating disease has been reversed.

When I learned that Dr. Brown testified in Congress, I decided it was time for me to find out why a program which has helped over 10,000 sufferers of arthritis was not being accepted by the Nation's medical establishment. I now think I know the answer to that question and I would like to tell you about it because it is something that Congress can do something about.

One of the first things that I did was to go see Dr. Shulman and Dr. Salans of NIADDK, where I learned that there were four research projects presently underway on the mycoplasma organism and its possible link to arthritis. But I also learned that there are no clinical trials presently underway and that there have not been any since the Boston study in 1971.

I began to realize that the real problem blocking the antibiotic treatment approach was that the Boston study failed.

The 1971 Boston study was a double-blind test of the effectiveness of tetracycline on rheumatoid arthritis in only 13 patients, was conducted for only 1 year, the patients were given oral antibiotics instead of intravenous antibiotics, and no effort was made to make certain all patients were taking some antiinflammatory. The study showed no significant positive effect from the tetracycline. If you have come through Dr. Brown's treatment program, you know why the Boston study failed—because the antibiotics were not given intravenously and because the study ended before the significant results are generally seen. I know how my 5-year recovery process would have measured up in a 1-year study.

Because of the negative results from this test, the medical establishment has, in my opinion, closed its mind to the antibiotic treatment approach.

I consider this to be a national tragedy—that 37 million arthritics may have to wait years for a treatment program which is presently available.

On or before June 1, 1984, Dr. Brown will be submitting an application for an NIH grant to conduct a clinical trial of the Antibiotic Treatment Program he has developed. It is essential that the policymakers, including Congress, become involved in the consideration of this grant application.

After billions of dollars have been spent on arthritis research, the Nation's arthritics still have no reason for hope. I have known what it is like to live without hope. I know what it is like to be given hope. And I know what it is like to have a disease reversed and to be able to live a full life again. If a clinical trial of this method of treatment is undertaken, I truly believe the suffering of millions of arthritics will come to an end because they will have the treatment program they deserve.

Thank you very much.

STATEMENT OF CLARENCE W. LEGERTON, M.D., CHAIRMAN, PUBLIC POLICY AND GOVERNMENT RELATIONS COMMITTEE

PREPARED STATEMENT

Senator WEICKER. Dr. Legerton. We will insert your prepared statement in the record.

[The statement follows:]

STATEMENT OF DR. CLARENCE W. LEGERTON

I am Clarence W. Legerton, M.D., Professor of Medicine at the Medical University of South Carolina at Charleston. I represent the American Gastroenterological Association, which has over 4,000 physician members, who are concerned with the improvement of patient care and research in the field of digestive diseases.

Mr. Chairman, the American Gastroenterological Association wishes to thank you and the members of this committee for your work last year in the support of digestive diseases research through this Appropriations Subcommittee. Not only did you provide sufficient funds to begin Digestive Diseases Centers, but you supported the underlying basic research programs in digestive diseases, as well as funding the various programs now underway at the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases, which have done so much to cause the forward advances in research in our field. These include the funding of the Digestive Diseases Advisory Board, the development of the Epidemiological Data program, and the support for the Digestive Diseases Education and Information Clearinghouse.

We sincerely hope that you will continue to support these programs, specifically by bill report language, and we also hope that you will provide bill report language indicating that the Digestive Diseases Research Centers, which were established by you last year, and which received specifically appropriated funds from the Congress, be continued, and receive an increase in funding to deal with inflation during the past year, and to continue building the program. We fully support the recommendations of the Coalition of Digestive Disease Organizations in this regard.

The biomedical research legislation, now making its way through both the House and Senate, contains authorizations for such research centers at levels of $8, $9, and $10 million for the three years that the bill will authorize NIH programs.

The bill has passed the full House, and has passed the Senate Committee on Labor and Human Resources, and is awaiting Senate floor action. As the provisions regarding these centers are the same in both bills, it is fully expected that when the bill is passed, the centers will be included.

Therefore, we request this Committee to fund the Digestive Disease Centers program at the levels that will be authorized in the legislation.

We are also recommending, Mr. Chairman, that the NIADDK be funded at a level of $550 million (this figure is agreed to also, I understand, by nearly all of the constituency groups which have an interest in the NIADDK), and we request a level of funding for fiscal year 1985 of $5,213.9 million for NIH, which is supported by very many scientific organizations in support of the "Ad Hoc Coalition on Biomedical Research."

I would like now to turn, Mr. Chairman, to four areas of research in which significant advances have taken place, and future opportunities have become clear.

They are:

1. Research Advance: IMPLICATIONS OF THE EXISTENCE OF SIMILAR PEPTIDES IN THE BRAIN AND GUT.

Background: During the past two decades a remarkable series of advances in the understanding of gastrointestinal physiology has occurred. This is in large measure due to the increasing number of gastrointestinal peptides which have demonstrated varied pharmacological properties. Many of these peptides have been shown to have significant hormonal effects in digestive processes and have provided considerable support to the concept of the digestive tract serving as an endocrine organ system. Perhaps what is even more intriguing is that hormones previously thought to act only on the digestive system have been found to affect the central nervous system as well.

Advances: Studies by investigators at the Center for Ulcer Research and Education, the University of Texas Health Sciences Center at Houston, Harvard University and other high quality research institutions have shown that many agents affect gastric and other digestive processes.

Of equal interest are the observations that many of the peptide hormones which have been shown to affect gastrointestinal function also affect the central nervous system.

Significance: The studies of brain and digestive system secretagogues have led to a better understanding of how gastrointestinal function is integrated. Studies of hormonal regulation at all levels of the digestive system are continuing and solid progress is being made. Understanding the relationship between the central nervous system and the digestive system may provide an insight into the basic mechanisms of many digestive diseases including functional bowel disease. The functional activity of peptides once thought to be the exclusive domain of the digestive system but now shown to function within the central nervous system as well tends to support the long-standing notion of conservatism in biological systems in which one agent or mechanism is used at a number of distant locations for similar or perhaps different functions.

Future Directions: It is anticipated that many advances in the treatment of secretory and motility disorders will arise from the study of digestive system hormones. It is hoped that some insight into the nature of psychogenically induced bowel dysfunction will occur as our understanding of hormones and their effect on the gut is clarified.

2. Research Advance: EXPERIMENTAL ACUTE HEMORRHAGIC PANCREATITIS WITH FAT NECROSIS IN MICE - treatment with leupeptin, pepstatin, chymostatin, and antipain, proteinase inhibitors of microbial origin, results in a distinct attenuation of the severity of the induced process.

Background: Acute hemorrhagic pancreatitis with fat necrosis (AHPN) is a severe form of human disease which is thought to result from autodigestion of the organ due to intraparenchymal activation of zymogens and formation of active proteinases. Dr. Lombardi and his colleagues at the University of Pittsburgh School of Medicine have recently developed an experimental model of AHPN in mice having clinical and anatomopathologic features that mimic closely those of the human disease. The onset of the experimental pancreatitis was shown to follow an intraparenchymal activation of zymogens, and indirect evidence was obtained that the latter may be triggered by cathepsin B_1, a lysosomal proteinase. They have now used this model to investigate whether administration to the animals of various proteinase inhibitors would affect the onset of the disease.

Findings: AHPN was induced in female mice fed a choline-deficient diet containing 1.5% DL-ethionine. The effect of the various proteinase inhibitors on the induction of the pancreatitis was evaluated using three parameters, the mortality of the animals, the appearance before death of a shock-like state, and the severity of the pancreatic pathology. Treatment of the animals with leupeptin, pepstatin, chymostatin and/or antipain, proteinase inhibitors of microbial origin, resulted in a distinct attenuation of the severity of the induced process, whereas Aprotinin (a bovine trypsin inhibitor) and chloroquine (a reputed inhibitor of cathepsin B_1 in tissue culture systems) had no effect.

Significance: Leupeptin, pepstatin, chymostatin and antipain are small peptides that have no side-effects and have been shown to also attenuate the severity of other experimental disease states. Therefore, their possible use in the therapy of hemorrhagic pancreatitis and other forms of pancreatitis appears to deserve consideration. In this regard, however, further work with other experimental models of pancreatitis may be warranted, since in the present model the induced pancreatitis is very severe and its onset often develops too rapidly to test adequately the effects of therapeutic agents.

3. Research Advance: DETECTION OF MINERAL NEEDS IN CHRONIC TOTAL PARENTERAL NUTRITION.

Background: Total parenteral nutrition (TPN) is a special means of providing certain patients with the proper amounts of the essential dietary nutrients by intravenous administration for the maintenance of health. TPN may be required for extensive periods in patients with (1) malabsorption for the intestinal tract, (2) extensive gastrointestinal surgery, or (3) hypercatabolic state continuing for a considerable time, such as extensive burns. In a patient unable to ingest, digest or absorb nutrients and not fed parenterally, starvation results in negative nitrogen balance and wasting of both muscle and viscera. This ultimately leads to dysfunction of the liver, muscle and immune system. Loss of 35 to 40% of lean body mass during such an illness usually results in death.

Much progress has been made during the past decade in the development of TPN mixtures and systems that provide appropriate levels of amino acids, vitamins and electrolytes. However, much remains unknown about the rate of depletion of essential trace minerals and levels needed by patients maintained on TPN for indefinite periods.

Advance: New information on requirements and reports of trace element deficiencies in patients fed by TPN has led to an increased awareness of the importance of providing proper levels of trace elements in TPN solutions, particularly when the parenteral route is the sole or primary source of nutrients for prolonged periods.

Significance: The ability to provide nutrients by parenteral means in amounts needed to maintain health of patients who cannot ingest, digest or absorb food, represents a major technological advance. Not only is total parenteral nutrition (TPN) extremely important in rehabilitation of critically ill, or surgically stressed, or other short-term conditions where food cannot be taken enterally, but the number of individuals requiring long-term TPN in order to live has reached approximately 1,000 and this number is doubling each year.

Future Direction: It is critically important then that the nutritional needs, both qualitatively and quantitatively (at least safe ranges and proportions) be worked out in order to permit normal growth, development and maintenance of health in these individuals.

4. Research Advance: ENTEROTOXIN AND MICROBIAL ADHERENCE IN INFECTIOUS DIARRHEAS

Background and Advance: It has recently become clear that a number of infectious diseases of the gastrointestinal tract are mediated by attachment of microorganisms to the intestinal mucosal surface of the host. Evidence suggests that, in each case, mucosal adherence is mediated by a specific "binding site-receptor site" interaction between surface structures elaborated by bacteria and naturally occurring elements of the host mucosal surface, respectively. Rapid progress has been made in localizing the colonization factor antigens (adhesions) of bacteria to a class of hair-like appendages termed pili or fimbriae. In contrast, very little progress has been made in defining the specific receptors on the intestinal surface of the host which mediate adherence. The best molecular candidates for the host receptors for pili are the carbohydrate portions of mucosal glycolipids or glycoproteins, molecules present in the apical epithelial cell membranes but also abundant in the intestinal mucous gel.

Future Direction: Proposed is support of multidisciplinary research on the structure, specificity, and role in enterotoxin and microbial binding of the carbohydrate and other potential recognition systems of the host receptor sites. These studies would very likely serve as a basis for developing a rationale for therapeutic intervention in diarrheas from infectious causes. Thus, protection against these diseases may be possible by developing appropriate mucosal surface receptor site analogs to either prevent colonization or dislodge the causative microorganisms from the intestinal mucosal surface of the host.

Mr. Chairman, I know that my colleagues who will be reporting to you today will indicate to you other advances that have taken place in this very dynamic field of research in digestive diseases.

We are all deeply grateful to you for your very strong support over so many years of digestive diseases research, and I want to add my personal appreciation to you for the very kind way in which you have handled my testimony in the past as I have appeared before you. May I also comment that your staff has been excellent in its work with us, and we appreciate that very much.

If there is any question I might answer, I would be pleased to do so.

Dr. LEGERTON. Thank you, Mr. Chairman. I am Clarence Legerton, chairman of the Public Policy and Government Relations Committee. I am chairman of the Committee on Public Policy and Government Relations.

Basically, Mr. Chairman, I am giving a synopsis of the material that has already been presented. Hopefully, in 3 minutes and 50 seconds, before we see too many different lights. I do not have a son running for President, nor do I have the gimmicks of Dr. O'Kieffe who will follow me in a moment. But I would like to urge your support and the committee's support for the NIADDK and the NIH more broadly.

Basically the American Gastroenterological Association joins other groups in asking NIADDK be funded at least at $550 million. We are particularly interested in certain programs of the NIADDK which deal with digestive diseases. Those are the Digestive Diseases Advisory Board, and we ask that that continue to be funded, and the Digestive Disease Information Clearinghouse.

A little more specifically, Mr. Chairman, we would specifically request the report language indicating that digestive disease research centers which were established last year and which received funds from the Congress be continued, and that they receive an increase in funding for this coming year of $5 million, and last, we recommend that the NIH itself, or parent body, of course, receive the funding that had been proposed by the Ad Hoc Committee on Biomedical Research, namely $5,213.9 million.

And in the minute and fifty seconds that my wristwatch tells me I have left, I would like to point out three advances in research that we have available to us. Many of the other witnesses will bring up other aspects of this, but I would like to limit myself to three.

In the last 15 or 20 years we have made great advances in our understanding of gastrointestinal physiology and how the digestive system works. We have discovered a number of hormones, peptide hormones, which act in the gastrointestinal system, and to our great surprise we have also found that these peptide hormones have an effect on the brain and central nervous system as well.

And with our increasing knowledge of the interrelationship between the digestive system and the brain, we think there are great opportunities to move forward on such things as abdominal cramps, abdominal pain, diarrhea, disturbances of motility, nausea, perhaps even vomiting.

These have caused a lot of physical suffering and, of course, account for a lot of absenteeism from work during the productive years of life. Another breakthrough we have is for pancreatitis which is a very bad disease. One of my patients has just expired from that, not pancreatitis but malignancy of the pancreas. But hemorrhagic pancreatitis is probably one of the more serious forms of pancreatitis. It is almost always fatal.

Just recently there have been some inhibitors which have been discovered which can seriously ameliorate the effects of this. So it looks like we have some possibility of cutting down on the effects and the severity and fatality of pancreatitis.

And, last, another branch comes from our study of patients that are maintained on total parenteral nutrition, what we call TPN. These individuals, who, unfortunately, for one reason or another cannot take food or nurishment by mouth and have to be maintained parenterally, as we say.

We have studied these people to find out their needs for amino acids, their needs for vitamins, and electrolites. But in looking at it further we are now beginning to delineate the need for certain trace elements, certain minerals, and if we can clearly delineate these we can prevent a lot of suffering, we can prolong life. And for the very unfortunate people who have had to be maintained on food and nurishment given by some route other than the oral route that you and I enjoy so much.

Thank you very much. We appreciate the interest and the previous help that you and the committee have given.

Senator WEICKER. Thank you very much, Doctor.

STATEMENT OF DONALD O'KIEFFE, M.D., MEMBER, LEGISLATIVE COMMITTEE, AMERICAN SOCIETY FOR GASTROINTESTINAL ENDOSCOPY

PREPARED STATEMENT

Senator WEICKER. Dr. Donald O'Kieffe, chairman of the American Society for Gastrointestinal Endoscopy.

Dr. O'KIEFFE. I am Donald O'Kieffe. I am a practicing gastroenterologist here in Washington and I work at George Washington Medical Center.

Today I come in the capacity of chairman of the legislative committee of the American Society for Gastrointestinal Endoscopy. This is made up of more than 3,000 members, that specialize in endoscope techniques for diagnosis and treatment of intestinal illnesses.

The first thing I would like to do is thank you and your committee for the swell support you have given NIH in the past, and especially, last year. This year we have made several recommendations that are listed on the fact sheet and attached to the testimony. I don't have time to go into them in any great detail, but I would like them entered formally in the record.

[The statement follows:]

STATEMENT OF DR. DONALD O'KIEFFE

I am Donald O'Kieffe, M.D., a gastroenterologist in the private practice of medicine in the Washington, D. C. area and a member of the Legislative Committee of the American Society for Gastrointestinal Endoscopy (ASGE).

ASGE is made up of more than 3,000 gastroenterologists and surgeons specializing in the use of fiberoptic endoscopes for the diagnosis and treatment of intestinal diseases.

We deeply appreciate the very strong support this Committee has given digestive disease research in recent years, especially last year.

I recognize the necessary limitation of time on these presentations and at this point, request that the full testimony be inserted for the record.

The American Society for Gastrointestinal Endoscopy makes the following recommendations regarding appropriations for digestive diseases research programs for fiscal year 1985:

1. That the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases be funded at a level of at least $550 million.
2. We support the Coalition of Digestive Disease Organization's recommendation that the following programs of the NIADDK be supported:
    a. Digestive Diseases Advisory Board
    b. Digestive Diseases Research Centers
    c. Development of a digestive diseases epidemiological data program
    d. Digestive Diseases Education and Information Clearinghouse.
3. Request for Centers Funding:

The authorization legislation establishing a program of Digestive Diseases Research Centers in the NIADDK is moving through the House and Senate, and contains levels of $8, $9, and $10 million for the fiscal years for which NIH (those programs requiring authorization) will be authorized.

We request the committee to fund the research centers program at the levels likely to be agreed to by the authorizing committees and the Congress (such authorizations are in both bills, and are likely to be retained in the Senate-House conference).

4. We request that bill report language take into consideration the remarkable surge forward in endoscopic research that has been occurring, as is detailed below.

5. That the National Institutes of Health be funded at a level of $5,213.9 million (we support the Ad Hoc Coalition for Biomedical Research in this matter).

Mr. Chairman, each year we come back with the same clear and simple message. What has set medicine in the United States apart from that in the rest of the world has been the unencumbered research produced by our scientists (especially the young scientists) following their own scientific inclinations and pursuing their own inner goals. From this has evolved important discoveries in every branch of science, including medicine. One major discovery after another has progressed from an idea to experimentation to theory. From theory to practical application is a short step. Advances in such diverse areas as pharmacology, molecular biology, nuclear physics, mechanical engineering, neuroanatomy, etc., have all contributed to our better understanding and treatment of disease states and has ultimately translated into better patient care.

Our hope is that this important thought will be kept in mind at the time of NIH funding. Each young investigator who stops or never starts on this scientific voyage is responsible for a pyramid of adverse effects ranging from what he doesn't accomplish to whom he doesn't influence.

Our organization is specifically interested in gastrointestinal research and specifically that which can be accomplished by the use of fiberoptic endoscopes. Not too many years ago, the only research which could be done on the gastrointestinal tract was limited to analysis of gastric secretions and stool. With the advent of fiberoptic instrumentation, the ability to penetrate deeper and deeper into the intestine allowed for access to organs which previously had been hidden and has opened up new vistas for gastrointestinal research. We hope we can now use this modality to play "catch-up" research.

I need not remind this Committee of the magnitude of the problem of digestive disease in this country. Colon cancer alone, just one of many gastrointestinal malignancies, is the second leading cancer in our nation. Digestive disease surgery is a leading form of elective and emergency surgery. Disability and absenteeism from digestive disorders accounts for billions of dollars in direct and indirect costs.

During previous testimony before your Committee, we have discussed the advances in gastrointestinal endoscopy, especially in the clinical arena. We have told you how gastrointestinal bleeding can be stopped by the use of lasers passed through the endoscope. We have mentioned how the pancreas and gall bladder can be visualized by endoscopic techniques. Varices of the esophagus can be obliterated by injection of a clotting substance into them and colon polyps (the precusers of colon cancer) can be removed without surgery. Gall stones trapped in the bile duct can be pulled out by wire baskets without surgery. These stones can also be dissolved by bile solutions or augmented by sound waves. This you have heard over the past few years.

This year I would like to elaborate on one example of how the funds allocated to the NIH has resulted in the development of a potentially important clinical tool.

In January 1982, a meeting was held at the National Institutes of Health to explore the research uses of fiberoptic endoscopy. The ASGE took part in this meeting and it became clear that a number of important opportunities were available for rapid movement forward.

One of the devices which was described at that meeting was an everting catheter (called the Toposcopic catheter or "topo"). This invention, which followed research which had been conducted for many years, is considered to be of great potential in the study and treatment of disorders of the gall bladder and pancreas. This particular device was developed for blood vessel catheterization by the Biomedical Engineering and Instrumentation Branch of the Division of Research Resources at the NIH.

In September 1982 the research committee of the ASGE took part in a basic research session held at the NIH and the potential uses of this catheter in gastrointestinal study was discussed. Following this conference, the topo was used experimentally in cannulations of the cystic duct of the dog (a very tortuous gall bladder duct) and it proved to be a very successful experiment.

An interagency agreement between NIADDK and the Division of Research Services at the NIH was then formulated to allow the Biomedical Engineering and Instrumentation Branch to begin fabrication of a catheter that would be suitable for use with the endoscope.

The potential uses of this catheter to study bile and pancreatic secretions, look for cancer cells and dissolve gall stones was very exciting and continued into 1984. This year a topo has been produced which can be passed through the small channel of an endoscope and initial studies with dogs catheterizing the Ampulla of Vater (entry of the pancreas and gall bladder ducts) have been successful. It is anticipated that clinical testing in humans will begin around May 1 by the Gastroenterology Section of the National Naval Medical Center (NNMC). The staff at the NNMC see the topo as a major breakthrough in gaining access to the biliary tree.

I am pleased to tell you that the importance of that January 1982 meeting was such that an effort has been made to publish the salient engineering and research papers in an appropriate journal. Arrangements have been made, in combination with the ASGE, to publish six manuscripts as two units in two different issues of the journal Gastrointestinal Endoscopy.

Technology has been developed in other areas. Probes to better examine the esophagus and evaluate its function will possibly ultimately help millions of Americans suffering from heart burn.

Balloons have been developed to measure colon contraction and function and may eventually help us better understand spastic or irritable bowel syndrome, one of the leading causes of disability and time lost from work in the United States.

Mr. Chairman, as you can see, these are exciting times in the field of endoscopy. I have referred several times in this testimony to the kind of support that has been given by this Committee, and without question that has caused the NIADDK to become much more active in the field. We want to assure you that the American Society for Gastrointestinal Endoscopy will give just as much support as is needed to the NIADDK to further its work.

In that regard, let me close by calling to your attention a new program which has been instituted by the ASGE. It is a Research, Training and Education Fund, which has been developed in conjunction with instrument manufacturers and pharmaceutical companies for the purpose of research, training and education as well as the assessment of new technologies. The ASGE obtained over $100,000 committed to this fund at its outset.

Again I want to thank you, Mr. Chairman, and members of the Committee for your clear interest and support of NIH and NIADDK.

Dr. O'KIEFFE. What I would like to do in the next couple of minutes, Mr. Chairman, is to introduce you to a medical device which I think very nicely illustrates how the basic research carried out at NIH can translate into a clinical tool which has profound ramifications for the treatment of disease.

What I refer to specifically is something called topostopic catheter. This is a small catheter which has been designed and developed at the biomedical engineering and instrument division at the NIH. It is a small self-inverting catheter. Actually two small catheters, one within the other. When you apply pressure at one end, the distal end actually extrudes. If you were to put your finger on it, were I to put pressure on it you would be able to feel it. This allows the catheter to be placed in small remote parts of the body.

It has already been used in experimental animals successfully. Within the past year it has been negotiated deep into the brain through the vascular system and it has been able to infuse high doses of chemotherapy to treat brain tumors. We are currently waiting for FDA approval in the digestive tract. At Bethesda Naval Medical Center, right now, they are designing studies to use this catheter to pass through flexible fiberoptic instruments, as you can see here, which is smaller than the one that was shown this committee 1 year ago, and advance it deep into the pancreas, pancreatic ducts, through the pancreatic ducts and into the gallbladder.

Now it is hoped that with the capabilities of removing pure secretions from these important structures we will not only promote basic research in the gallbladder and pancreas, but we will also be able to detect diseases such as cancer of the pancreas and other diseases much earlier.

We also hope to use this catheter for dissolving gallstones. So, it has some therapeutic implications.

We are very excited about this. It can be passed through an instrument and, therefore, passed deep into the human body. I think this is a small, but rather dramatic example, of how the system works. How research at NIH translates through several steps into a clinical tool, and coupled with another device, we are able to promote basic research and also help the patients clinically, and therefore, improve patient care.

So, I would just mention that today, and hope that in your forthcoming deliberations in your unenviable task of assigning priorities to these valuable dollars that we are talking about, that you will take the recommendations into consideration. Thank you.

Senator WEICKER. Thank you very much. Thank you for your testimony.

STATEMENT OF JOHN P. PAPP, M.D., F.A.C.P., CHAIRMAN, LEGISLATIVE AFFAIRS COMMITTEE OF THE AMERICAN COLLEGE OF GASTROENTEROLOGY

PREPARED STATEMENT

Senator WEICKER. Next is Dr. John Papp, the national affairs chairman of the oversight committee of the American College of Gastroenterology. Before you begin we will place your statement in the record.

[The statement follows:]

STATEMENT OF DR. JOHN P. PAPP

Chairman Weicker, I am Dr. John P. Papp, a physician in private practice specializing in the treatment of gastrointestinal disease. Today I come before you as the National Affairs Chairman of the American College of Gastroenterology. The American College of Gastroenterology has a deep commitment to clinical research and its subsequent application to the treatment and care of patients ill with gastrointestinal disorders.

Every year millions of Americans experience diarrhea, which may incapacitate them from working and caring for their home. It has recently become clear that a number of infectious diseases of the gastrointestinal tract are mediated by attachment of microorganisms to the intestinal mucosal surface. Evidence suggests that in each case mucosal adherence is mediated by a specific "binding site" - "receptor site" interaction between surface structures elaborated by bacteria and naturally occuring elements of the host mucosal surface. Progress is being made in localizing the colonization factor antigens (adhesins) of bacteria to a class of hair-like appendages termed pili or fimbriae. In contrast, very little progress has been made in defining the specific receptors on the intestinal surface of the host which mediates adherence. The best molecular candidates for the host receptors for pili are the carbohydrate portions of mucosal glycolipids or glycoproteins, molecules present in the apical epithelial cell membranes, but also abundant in the intestinal mucous gel.

The American College of Gastroenterology supports a multidisciplinary research on the structure, specificity, biological function, distribution, genetic control, age of development, and role in enterotoxin and microbial binding of the carbohydrate and other potential recognition systems of the host receptor sites. These studies would very likely serve as a basis for developing a rationale for therapeutic intervention (vaccines) in diarrhea from infectious causes.

Gluten-sensitive enteropathy (Celiac Sprue, GSE) is a disease that affects the small intestinal mucosa in children and adults. It results in the malabsorption of most nutrients when gluten is ingested. GSE is known to be activated by protein(s) in the gliaden fraction of wheat and similar proteins in rye, oats, and barley. How gliadin(s) result in epithelial cell damage is unknown. Little is known regarding the nature, regulation, and specificity of the immune response to these proteins. The genetic control of immune response to gluten proteins has been studied in mice. These studies revealed that two separate genetic regions determine the mouse antibody response to gluten proteins. This finding, along with the finding that major histo-compatibility complex alleles (HLA-B8, -Dw3, and -DRw3) occur at high frequency in patients with GSE suggests that specific genes may control immune responses to dietary gliadin in man.

The study of GSE provides a unique opportunity to study the relation between a particular defined antigen, the gluten protein, and the immunogenetic factors which control responses to that antigen in the gastrointestinal tract.

In the time frame of medical research, advances in our understanding of hepatitis B have moved with breathtaking rapidity. Within a span of 15 years, an antigen of initially unknown origin and significance has served to elucidate the structure, mechanism of production, and transmission pattern of the hepatitis B virus, has served to almost eradicate hepatitis B as a determinant in post-transfusion hepatitis and has evolved into an enormously effective vaccine for the prevention of hepatitis B, and possibly the prevention of hepatocellular carcinoma. The epidemiological link between HBV and hepatocellular cancer has been strengthened by large studies in Japan and China but not in this country, where the incidence is much lower. A study of 2,985 Tokyo workers followed for five years of a long-term study, showed a 28-fold increase in deaths from HCC in HBsAG positive versus negative controls. In 20,000 Chinese workers, the findings were similar. However, what is happening in the prolonged carrier state is a challenging question that is starting to be understood. Human carriers of HBV are showing integration of viral DNA into the liver genome when the carrier state is of long duration, but not in the short term. Although animal models having HBV-like viruses and showing high incidences of HCC have been found (woodchuck, ground squirrel, Peking duck), they may not mimic the human carrier condition because only low prevalence of viral DNA integration has been found in the woodchuck cariers; chimpanzee carriers of 10-14 years are still not showing integration. Eventually, the worldwide prophylactic use of the HBV vaccine may prevent chronic hepatitis, but the current availability of carriers makes the timing opportune for study.

In human liver biopsy specimens from chronic active hepatitis HBV-carriers, viral DNA was found in a free form in the nucleus of five carriers of HBV who had evidence of the carrier state for less than two years, whereas in five longterm carriers, integrated HBV DNA was found in the liver. In human primary hepatocellular carcinoma, the DNA extracts from all tumors coming from patients who were HBV carriers showed HBV-DNA integrated into the host genome.

There are approximately 180 million HBV carriers world-wide (750,000 in the U.S.A.). Because chronic active hepatitis may be a sequela of the carrier state in 1-5%, and because large numbers of Asian immigrants with high carrier rates have recently entered the country, it becomes important to learn whether unresolved CAH may be a forerunner, or possibly, a precancerous state. Treatment of CAH remains controversial. By using research techniques now available for delineating the natural history of HBV infections, a prospective follow-up of patients with chronic disease may determine whether current or experimental treatments prevent or exacerbate viral integration into the liver cell.

As you've heard this morning, there are many other areas in need of research in the gastrointestinal tract. Without appropriations, these areas of research could not be done. The American College of Gastroenterology recommends for FY 1985 appropriations: 1. $550 million dollars for NIADDK; 2. $5,213 billion dollars for the NIH; 3. continued funding of the Digestive Diseases Advisory Board, Data Program, and the Digestive Diseases Education and Information Clearinghouse; 4. continuation and expansion of the newly established Centers of Excellence Programs at NIADDK.

Mr. Chairman, this concludes my remarks. The American College of Gastroenterology is grateful to your Subcommittee for the support you have provided for digestive programs at NIH, and look forward to continuing our productive relationship.

I am pleased to respond to any questions you may have.

Dr. PAPP. Mr. Chairman, I come to you as a representative of the American College of Gastroenterology. I am in private practice in Michigan.

The American College of Gastroenterology is interested in the day-to-day care of patients, and we are very interested in clinical research as it relates to subsequent therapies with people who have G.I. disease. Because of the time restriction I, as the previous speaker would like to restrict my discussion to three diseases.

The most common one, I think we all have had, is diarrhea. In the last few years we have learned that bacteria attach themselves to the intestinal tract and we know why the bacteria attach to the intestinal tract but we are not sure why the body allows it to attach the receptor in the body. We feel that if we had appropriate funds for research that we would learn more about these receptor sites in the G.I. tract and, therefore, develop vaccines to treat these infections.

Another disease which presents itself is diarrhea celiac sprue and that is a disease where the substance, gliadin, results in destruction of the bowel itself, the small intestine. These affect children as well as adults. It will cause them to malabsorb food and lose weight and have diarrhea.

We feel if we had clinical research funds to evaluate the cause of the gliadin disturbance of the bowel that we would solve and be able to treat this disorder.

Last, I am sure you have read a great deal about hepatitis B virus. In the last 15 years we have made galactic improvement in our knowledge of hepatitis B.

The problem that we now face is the concern that hepatitis B may actually cause cancer in humans. There are 150 million people in the world with hepatitis B virus in their bloodstreams and some of those people get chronic liver disease.

We've been concerned that some of these people go on to chronic hepatitis and then subsequently liver cancer; and we would ask that perhaps funding be available to study the sequilae of hepatitis B as a virus works within our own nucleus in our liver cells and perhaps learn why it causes cancer of the liver.

Without funding for these studies—we only picked three this morning and you heard about three others—we would not be able to advance our knowledge of digestive disease.

We, as others, would support your committee's help in allowing us to have $550 million for NIADDK, the funding of $5.213 billion for NIH, and finally, I asked this last year when we had your support that you continue funding for the Digestive Diseases Advisory Board and that a program the Digestive Disease Clearinghouse and continue and expand the centers for excellence.

We would recommend that appropriations up to $8 million for pending authorized legislation be considered for new centers of excellence in digestive disease.

I have run out of time. And I sincerely thank you for allowing to present it.

Senator WEICKER. Thank you, Doctor, for your testimony.

STATEMENT OF PEYTON E. WEARY, M.D., THE AMERICAN ACADEMY OF DERMATOLOGY, INC.

PREPARED STATEMENT

Senator WEICKER. Our next witness is Dr. Peyton Weary of the American Academy of Dermatology. Welcome.

Dr. WEARY. Thank you, Mr. Chairman, for the opportunity to be here. I am chairman of the department of dermatology. I have submitted some written testimony concerning a number of institutes. As in the past, we usually talk about a number of institutes, because skin research involves a number of different disciplines and it is appropriate for us to do so. I ask that testimony I have submitted be entered into the hearing record. I would, therefore, like to make a few extemporaneous comments.

[The statement follows:]

STATEMENT OF DR. PEYTON E. WEARY

Mr. Chairman, I am Peyton E. Weary, M.D., Chairman of the Department of Dermatology at the University of Virginia School of Medicine and Washington Representative from the Council on Governmental Liaison of The American Academy of Dermatology. I am presenting this testimony on behalf of The American Academy of Dermatology, whose membership of over 6,000 represents the majority of American Dermatologists, and on behalf of The Society for Investigative Dermatology, the representative organization for the dermatologic biomedical research community.

I would like to begin by expressing the profound appreciation of the dermatologic research community for the strong financial support granted by the Congress to the National Institutes of Health last year. This support has greatly enhanced the stability of the N.I.H. and has been most encouraging to those in the biomedical research field.

We are pleased to inform this subcommittee that an updated report on research needs and priorities in dermatology has been submitted for publication in the Journal of the American Academy of Dermatology and we hope to present a copy of this report to each member of this subcommittee as soon as it is available. I would like, however, to summarize for you briefly some highlights from this report which will serve to emphasize my statement last year in my testimony that "we are entering a most exciting and productive era of dermatologic research."

CANCER

1. A type of leukemia which preferentially attacks the skin called cutaneous T-cell lymphoma has received much attention at the National Cancer Institute and other dermatology research centers in recent years. This disease is one which has been most resistant to treatment in the past. A new treatment is now being tested with significant promise in which blood is removed from the patient, fractionated into several components and the white blood cells responsible for the disease irradiated with long-wave length ultra-violet light which destroys the harmful white cells but spares other useful ones. The irradiated blood is then

reintroduced into the body. This ingenious new treatment may be helpful in other disorders associated with abnormal white cell populations as well.

2. Certain types of viral warts can develop into cancer of the skin. Studies underway in the Dermatology Intramural Program of the National Cancer Institute indicate these warts may respond to injection of interferon whereas previous types of therapy were unsuccessful. Interferon is a naturally-occurring anti-viral substance produced by the body which has been a target for much NIH-supported research in recent years. Furthermore, an article in the April 5, 1984 issue of the New England Journal of Medicine indicates that wart virus may play a role in causing cancer of the cervix. This is yet another example of how research in one discipline may lead to significant advances in understanding about other diseases.

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Last year, the Congress requested an increased emphasis on research for this tragic disabling disease and this has in fact prompted new initiatives. Recent studies from several laboratories supported by N.I.H. funds have identified specific deficiencies of normal components of skin in the skin of individuals with dystrophic epidermolysis bullosa here to fore unrecognized. This study utilizes new techniques in immunology which have only recently become available through N.I.H.-supported research.

HERPES SIMPLEX INFECTION

I would like to cite one other example of significant research which will emphasize the interdisciplinary nature of skin related research. Herpes simplex infections have gained major recognition in recent years because of their high incidence in the population and their resistance to treatment. One problem has been the inability to rapidly confirm the presence of such infections. Ordinarily using the best available tissue culture techniques, the presence of the virus could only be precisely confirmed in from three to ten days. Research conducted in the Infectious Diseases Branch of the

National Institute of Neurological and Communicative Disorders and Stroke has led to the development of a rapid tissue culture method which can confirm the presence of the virus in 24 hours. This could greatly enhance our ability to confirm and treat this disorder more rapidly.

These are only examples of the exciting research being conducted in the field of dermatology which may have profound implications for reducing the burden of illness from skin disease in our society.

Mr. Chairman, as in the past, I would like to briefly note our interest in a number of institutes which support research in skin disease as follows:

1. THE NATIONAL INSTITUTE OF ARTHRITIS, DIABETES AND DIGESTIVE AND KIDNEY DISEASES

This institute last year received a substantial increase for which we applaud the wisdom of the Congress in recognizing the impacted nature of the institute and its broad mandate to conduct research in a number of diseases which are disabling and chronic. We endorse the conclusions and recommendations of the coalition supporting NIADDK funding, of which our organizations are members, in asking for a level of funding for this institute for FY 1985 of $550 million (See attached document). We believe this level of funding to be appropriate to maintain stability and allow for modest growth.

2. THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

This institute also received a generous increase from the Congress last year which was most justified because of the unacceptably low level of funding of approved grants in prior years. We believe the President's proposed budged for FY 1985 of $325.3 million would be retrogressive and once again lead to inadequate levels of funding. We would urge a substantially higher amount to maintain stability and permit reasonable growth.

3. THE NATIONAL CANCER INSTITUTE

The Intramural Dermatology Program which is located in the National Cancer Institute is at the forefront of research in skin disease and also a vital element in sustained training of competent young investigators in skin research. We would urge that funds be provided to permit orderly expansion of this fine program. In addition, the dermatologic community has become increasingly aware of a substantial increase in malignant melanoma, the most lethal of all types of skin cancer. This has prompted a number of new studies of this tumor including studies of the effect of environmental factors upon the skin and the possible relationship of such environmental factors as sunlight upon the immune system which plays a major role in protection of man from cancer.

4. THE NATIONAL INSTITUTE ON AGING

We were most gratified to see the substantial increase in funding for this institute granted by the Congress last year and feel such support for problems of this rapidly increasing segment of our society was well justified. Dr. Williams appeared last fall before the Association of Professors of Dermatology and expressed his interest in supporting research in the skin problems of the aged which produce a substantial economic burden for the aged population. We are pleased to learn of his interest and hope the Congress will continue to support such research generously.

5. THE NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH

We continue to be disappointed in the levels of funding granted this institute for research and training. As we pointed out last year there is probably no research activity which could have more of an impact upon reduction in economic losses to society than research in occupational diseases because these clearly account for a major loss in the productivity of our industry and agriculture. We hope that this institute can maintain the initiative in occupational skin disease begun three years ago but doubt this will happen unless funding is substantially increased. The institute's leadership is well aware of the importance of occupational skin disease and we feel certain would wish to maintain the momentum already established if funds are available.

6. THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

We are pleased to learn of this institute's interest in the impact of environmental agents upon the skin and hope to establish increased collaborative efforts between the dermatology research community and the institute.

Thank you for the opportunity to express both our appreciation to this subcommittee for its continuing strong support for productive research and some of our perceptions of areas where increased support will be cost-beneficial.

FY 1985 Budget Proposal for the National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases (NIADDKD)

By

The NIADDKD Coalition

The voluntary health agencies and professional societies on the attached list join in urging the Congress to approve a funding level of at least $550 million for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDKD) for Fiscal Year 1985. A fact sheet is attached discussing the Institute, its accomplishments, and its needs for the future.

We deeply appreciate the hard work and support of so many Senators and Representatives, and their staffs, over many years, in support of the National Institutes of Health (NIH) generally and NIADDKD in particular. Historically, Congress has provided the initiative that has permitted NIH to grow and flourish. This initiative was evident in FY 1983 and FY 1984, and we urge Congress to continue its position of strong support for FY 1985.

We recognize that biomedical research is interdependent, and we all support the overall effort of the NIH as well as the programs within NIADDKD specifically. At a time when unprecedented opportunities are available, growth in research funding should allow full support of research efforts and adjustment for inflation. Anything less will have a direct, adverse impact on America's health far into the future.

Please call on us, individually or collectively, for any information or assistance you may need regarding funding for NIADDKD. Thank you for your interest and support.

SUPPORTING ORGANIZATIONS

American Academy of Dermatology, Inc.
American Academy of Orthopaedic Surgeons
American Brittle Bone Society
American Celiac Society
American College of Gastroenterology
American Diabetes Association
American Gastroenterological Association
American Juvenile Arthritis Organization
American Liver Foundation
American Rheumatism Association
American Society for Artificial Internal Organs
American Society for Bone and Mineral Research
American Society for Gastrointestinal Endoscopy
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Nephrology
American Society for Parenteral and Enteral Nutrition
American Society of Transplant Physicians
American Society of Transplant Surgeons
American Thyroid Association
American Urological Association, Inc.
Arthritis Foundation
Arthritis Health Professions Association
Center for Ulcer Research and Education
Children's Liver Foundation
Coalition of Digestive Disease Organizations
Cooley's Anemia Foundation
Cystic Fibrosis Foundation
Dean Thiel Foundation
Dystrophic Epidermolysis Bullosa Research Association (DEBRA)
Endocrine Society
Gluten Intolerance Group
International Association for Enterostomal Therapy
Inter-Society Council on Kidney and Neurological Diseases
Juvenile Diabetes Foundation
Lifelong Foundation
Lupus Foundation of American
National Foundation for Ileitis and Colitis
National Kidney Foundation
North American Society for Pediatric Gastroenterology
Orthopedic Research Society
The Paget's Disease Foundation, Inc.
Pediatric Liver Research Foundation
Renal Physicians Association
Society for Gastrointestinal Assistants
The Society for Investigative Dermatology
The Society for Surgery of the Ailmentary Tract
United Scleroderma Foundation

April 1984

THE NATIONAL INSTITUTE OF ARTHRITIS, DIABETES, AND DIGESTIVE AND KIDNEY DISEASES (NIADDKD) NEEDS $550 MILLION FOR FISCAL YEAR 1985

What is the mandate of NIADDKD? To support research into a wide range of chronic, disabling, crippling, and debilitating diseases which account for a large portion of the total burden of illness in America.

The Institute's programs are divided into eleven areas: arthritis, musculo-skeletal diseases, skin diseases, diabetes, endocrinology, metabolic diseases, digestive diseases, nutrition, kidney diseases, urology, and hematology. Included in the programs of these areas is research on cystic fibrosis, Paget's disease of bone, osteogenesis imperfecta (brittle bone disease), lupus, Cooley's anemia, hemophilia, scleroderma, liver disease, sickle cell anemia, psoriasis, dystrophic epidermolysis bullosa, dwarfism, and osteoporosis, as well as treatment for traumatic injuries and many other health concerns. It is safe to say that every American family can benefit from the successful fulfillment of the mission of NIADDKD.

Has NIADDKD succeeded in the past? During the 1970's and 1980's, due to the support provided by Congress, Institute-funded research produced major advances in nearly every area. Examples: development of artificial joints; control of gout; synthetic production of human insulin, somatostatin, and growth hormone, development of portable automatic insulin infusion pumps; new treatments for gastric and duodenal ulcer; advancement of endoscopic research; development of kidney transplantation and improved techniques of dialysis; successful induction of ovulation and pregnancy through hormone treatments; prenatal diagnostic tests for sickle cell anemia; and major improvements in the treatment of skin disease.

What are the prospects for the 1980's? Scientifically, they are still excellent. Major breakthroughs in our basic understanding of immunology, genetics, recombinant DNA, and the roles of hormones, neurotransmitters, and other substances are being translated into practical improvements in all areas of the Institute's responsibility. The 1980's show great promise of allowing medicine to move from treatment of symptoms, to attacks at the underlying causes of chronic illness.

Is the President's budget adequate for NIADDKD? No. The recommended increase of 2.8% for FY '85 would force a significant reduction in the pace of NIADDKD research. Although the Institute did receive an increase in its 1984 and 1983 budget, this followed a reduction in FY 1982.

The budget proposed for FY '85 permits only a 2.8% increase. The number of new research grants funded will be 100 fewer than FY 1984 and about 80 fewer than the average number of the past seven years. Only 28% of all approved applicants will be funded and that assumes a "negotiated" reduction of 15% in the new grant's size imposed by NIH. If grants were funded at study section approved budget levels, only 11% of all approved grants would be funded. Grant applicants with scores of greater than 170 would not be funded under the President's budget. Over the past seven years (FY 1978 -- FY 1984), 40% of approved grants have been funded and applications have been funded with scores of up to 200. These facts clearly indicate that a great deal of very high quality research will go unfunded in FY 1985 if the President's budget were adopted. We estimate that at least 300 grants with excellent scores of 200 or better will go unfunded under the President's budget.

This Institute is especially hard hit by the FY 1985 budget of the Administration. It must reduce new grants awarded by about 15% below approved rates and cut continuation grants by 8%. It is the only Institute funding far fewer new grants under the FY 1985 budget proposal than in FY 1984. This Institute will also be able to support, in total, about 75 fewer research trainees than in FY 1984 and center grants will be reduced by about 10%.

Across-the-board reductions in grant payments may allow more grants to be funded, but reductions do not increase the amount of scientific research being performed. Instead, research projects are shortchanged, and the quality of science is reduced.

Because of inadequate funding, important research opportunities are being lost, and these trends, plus reduced training money, are convincing many good scientists that it is no longer advisable to plan on a career in biomedical research. Current funding patterns will directly translate into additional, but avoidable, deaths and disabilities during the latter part of this decade.

What is needed for NIADDKD? A $550 million budget for FY 1985 is needed. Such a budget would restore cuts in new and non-competing research grants of 15% and 8% and in centers of 10% It would support the same number of trainees and career awards as in FY 1984 and restore about $5 million of cuts in the intramural program which has been one of the stellar research enterprises at NIH. A $550 million budget would also allow the Institute to fund 37% of all approved research grants, (3% lower than the seven-year average rate of award) and to fund research grants to a payline of 190 (still 10 points below the seven year average).

A $550 million budget for FY 1985 would, in summary, restore the program to FY 1984 levels, and allow an additional $10 to $12 million dollars to support all grants with scores of up to 190. Without such modest real growth, important opportunities will be missed and our scientific effort will be eroded. This proposal also achieves the important objective of funding excellent research, that with scores of about 190. To do less will leave much excellent research unfunded and result in opportunities being lost or delayed.

Background Data

NIADDKD RESEARCH GRANT DATA

Fiscal Years	No. of Research Grants	Award Rates	Payline To Which Grants Made
1978	685	42%	223
1979	769	50%	230
1980	698	43%	221
1981	761	41%	210
1982	645	30%	190
1983	777	38.8%	185
1984 estimate	756	33%	175-180
1985 estimate (Pres.)	647	28%	170
1985 Coalition Proposal	800+	37%	190

The average number of new grants for the period FY '78 - FY '84 is about 730, the average award rate for that period is about 40% and the average score to which grants are paid in that period is about 201.

NIADDKD BUDGET HISTORY

Fiscal Years	Total Institute Budget	Rate of Growth in Budget
1978	260 million	19%
1979	302 million	14.5%
1980	341 million	13.3%
1981	369 million	8%
1982	368 million	-1%
1983	413 million	12.5%
1984	462 million	12%
1985 President's Budget	475 million	2.8%
1985 Coalition Proposal	550 million	18.8%

Supplementary Information on Occupational Skin Disease to Accompany Testimony
of Payton E. Weary, M.D. on Behalf of the American Academy of Dermatology, Inc.
and The Society for Investigative Dermatology

NIOSH FUNDING HISTORY

	POSITIONS	RESEARCH	(GRANTS)	TRAINING	(GRANTS)	PROGRAM SUPPORT	TOTAL (THOUSANDS)
1978 Comparable	913*	44,397	(3,900)	8,355	(7,000)	3,513	56,265
1979 Operating	913*	47,966	(6,070)	10,832	(9,400)	3,759	62,557
1980 Operating	932*	62,195	(7,040)	13,882	(12,900)	4,305	80,382
1981 Continuing Resolution with Pay Raise	937*	63,933	(5,754)	14,318	(13,160)	4,705	82,956
1981 Recission Budget . .	841**	57,252	(4,740)	2,763	(2,109)	4,205	64,220
1981 Operating	841**	54,972	(4,740)	8,762	(7,602)	4,174	67,848
1982 Operating	784**	53,486	(4,740)	5,760	(5,760)	2,816	62,062
1983 Operating	783***	49,545	(4,740)	5,760	(5,760)	2,179	57,484
1984 Presidents Budget .	773	52,288	(6,501)	0	0	2,332	54,620
1984 CONFERENCE REPORT		53.8		8.8		2.3	64.9

* Includes 9 reimburseable positions.

** Includes 6 reimburseable positions.

*** Includes 11 reimburseable positions.

Dr. WEARY. I would like to thank the committee for the generous support which they have provided for the National Institutes of Health this past year. I unfortunately do not have with me a report on research needs and priorities in dermatology which was requested by the Congress previously. The report has been completed but it has not been published, and when it is available we will make it available to the committee. It will, however, document a number of exciting advances in dermatologic research and opportunities for new research in many different areas. We would endorse the report of the coalition for outside interest groups concerned with NIADDK funding which calls for $550 million, and we feel that this amount is necessary to maintain stability and allow for modest growth.

I would also like to endorse the report, the testimony of Sheldon Wolff, in testimony to the NIDIA, because we feel it is definitely underfunded.

I would like to concentrate my remarks on what I consider to be a neglected institute, the National Institute of Occupational Safety and Health.

Mr. Chairman, I would like to provide for you a fact sheet which traces the level of funding for what I would characterize as a "Cinderella Institute" which is still awaiting an invitation to the ball. I think it is evident from this information that this Institute has not received the type of support which it definitely deserves.

It is clear, if you look at the levels of funding, that they are not even up to the level of the 1981 recession budget this past year, even though there was a substantial increase.

Three years ago at the request of the Congress, this Institute undertook a substantial initiative in providing support for occupational skin disease. We repeatedly testified before the Congress on the importance of occupational skin disease, which accounts for 45 percent of all occupational illness and 25 percent of time lost from work as a result of occupational illness.

This initiative undertaken was very important and in response to this a number of very good grants were received by the Institute and funded. Unfortunately, now this money is no longer going to be available unless there is a new infusion of funds into this Institute.

We have talked with the people in charge of the Institute. They are very much aware of the importance of occupational skin disease and I feel quite certain would wish to maintain the initiative and impetus that has already been started.

But unless adequate funds are provided for the National Institute for Occupational Safety and Health I feel that this will not happen and we will be back again in a situation we were prior to the initiative.

I thank you very much for the opportunity to present this testimony to you.

Senator WEICKER. Dr. Weary, thank you very much for taking time to be with us here today.

STATEMENT OF ARLENE PESSAR, R.N., EXECUTIVE DIRECTOR, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION

ACCOMPANIED BY CAL LARSON

Arlene Pessar? Come on up here. Arlene is the executive director of the Dystrophic Epidermolysis Bullosa Research Association.

Ms. PESSAR. If you think it's hard to say, let me tell you, it's a heck of a lot harder to live with.

Senator WEICKER. I have no doubt about that. With you is?

Ms. PESSAR. Cal Larson.

Senator WEICKER. Cal, nice to have you with us.

Ms. Pessar, we will insert your statement in the record.

[The statement follows:]

STATEMENT OF ARLENE PESSAR

My name is Arlene Pessar. I am grateful to have this opportunity to talk with you again about Epidermolysis Bullosa (EB). EB is a group of incurable, chronic and life-threatening genetic diseases which cause blistering and destruction of the skin and mucous membranes. EB is an "orphan" disease that threatens the lives of approximately 50,000 young children and adults in the United States. I am the founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association (D.E.B.R.A.). We are a national voluntary organization of patients, families and concerned individuals representing the needs of persons who suffer from EB. My son, Eric, has lived with a severe form of EB since birth 13 years ago.

When I walk into this room I feel as if I am among friends, because indeed you have been very generous in your support of NIH. More importantly, this Committee and the Congress has been extremely concerned about the quality of life for children and families who suffer from this painful and debilitating disease.

The impetus for research on EB has occurred largely as a result of D.E.B.R.A.'s labors. In the past two years it has reached even greater heights because of the concern shown by members of this Committee and their staff. And for this we are deeply appreciative. However, I hope after hearing my testimony you will see that serious problems still exist and why increased federal support is desperately needed in order to expand the knowledge and understanding of this complex group of diseases.

In December 1983, as a result of specific language in the final bill reports "directing NIADDK to expand its research programs on EB and related diseases", an advisory group met to discuss how NIADDK could best encourage additional research in EB, and other blistering diseases. Although separate figures are not available for the Skin Diseases program, it is estimated that of the $462 million budgeted for NIADDK in FY 1984, approximately $11 million will be used to support research projects on ALL skin diseases, such as psoriasis, acne, pemphigus, and other chronic dermatologic disorders. Therefore, it was generally agreed by this advisory group that even though the Institute did receive an increase for 1984, the Skin Diseases Program does not have sufficient funds to support new areas of research, such as EB. (In March I provided the Chairman with a summary of this meeting. I would like a copy of my letter to be made part of the record - see attached).

Unfortunately, the picture for this year is even worse as the budget proposed for FY 1985 would significantly force a further reduction in the pace of NIADDK research. The number of new research grants funded by the Institute will be 100 fewer than in 1984. In order for NIADDK to continue its impressive progress, its appropriations must be increased.

In order to develop better understanding, treatment and prevention of EB, scientists must understand the basic structure and functions of the skin and its appendages. Another area of significance is to increase the understanding aimed at locating the gene or genes that cause EB so diagnostic methods for genetic testing can be developed. Because so many of these patients are missing as much as 50% of their body surface, the basic mechanisms relating to wound-healing, infection and cancer must be addressed. Anemia, malnutrition and growth retardation are also critical factors relevant to EB. At the present time, no research is being done on the nutritional status of these patients -- yet these problems account for the high mortality and physical and developmental disability in many of these young patients.

Scientifically the climate for research in EB is ripe. New advances in technology are now available which can be directly applied to EB. For example, the development of monoclonal antibody technology has an enormous impact on EB and other blistering diseases. Such advances allow for faster and more accurate diagnosis -- no trivial matter since 75% of all EB patients are misdiagnosed.

Other advances in endocrine and genetic research can also be applied to EB. If scientists can synthesize insulin and human growth hormone using recombinant DNA techniques, and isolate the particular gene responsible for PKU, it is not so farfetched to believe that answers to EB can be discovered as well.

Mr. Chairman, we all agree that medical research is an investment which brings human and financial rewards which far exceed their expenditures. Every year millions of dollars are spent to care for patients who suffer the devastating effects of EB. Every year thousands of people are hospitalized because of its complications. Hundreds of newborns and young children have died because of the debilitating symptoms. We all know that when scientists are looking for an area to work on, they go where they know they will have a chance of getting funded. If ever there was a time to "prime the pump" and "justify a need", this is the time! A small investment made now will result in millions of dollars and lives being saved over the next few years.

Therefore, in keeping with the recommendations made by the other voluntary health agencies and professional societies that are concerned about NIH funding, we also endorse a level of, at least, $550 million for the NIADDK.

Because I know the only real hope for my son and the other children who suffer from EB depends on advances in basic research, I respectfully request that an additional $2 million be provided over the next three years to support new research that must be expended specifically on EB. Additional funding of this magnitude would only support a few new research grants during this period of time. I am convinced that once a critical mass of ongoing research has been established, the future for EB sufferers and their families will begin to appear more optimistic. Mr. Chairman, we know these are trying economic times, but we also know that without this additional financial support, research on EB will continue to be a slow and painful process.

I end this statement with a quote from you: "YOU CAN'T PUT HOPE ON HOLD!" I pray you will remember this when you are making your final recommendations. Thank you.

FACT SHEET

1. Epidermolysis Bullosa (EB) is a complex group of genetic disorders which causes blistering and destruction of the skin and mucous membranes in both the gastrointestinal and respiratory tracts. In many cases, its symptoms resemble severe burns.
2. EB may cause a lifetime of pain, scarring, deformity, contractures, malnutrition, anemia, growth retardation, gastro-intestinal problems, dental problems, corneal erosions and carcinoma. In the severest forms premature death is inevitable.
3. It is estimated that 50,000 Americans, mostly young children and adults, suffer from EB. Another 100,000 - 150,000 may be carriers. There is no test to determine who the carriers are. Parents at risk are seldom referred for genetic counseling.
4. Disfigurement and social stigma cause many patients to lead seclusive lives. High divorce rate and broken family relationships are very common and widespread.
5. Exhorbitant medical costs. Usually not covered under insurance plans, SSI or medicaid programs. Many states do not recognize EB under existing Crippled Children's or Developmental Disability programs.
6. High rate of institutionalization of infants and young children.
7. Information on EB scarce; seldom distributed.
8. Families run all over the world searching for unproven cures and miracles.
9. Limited treatment. No known cure. Little research funds available to study the causes, treatment and cure of Epidermolysis Bullosa.

March 9, 1984

Honorable Lowell Weicker, Jr.,
Chairman
Subcommittee on Labor-Health and
Human Services and Education
Appropriations
U.S. Senate
Room 1108 Dirksen
Washington, D. C. 20510

Dear Senator Weicker:

I am writing at this time to share with you recent developments concerning Epidermolysis Bullosa because of the language that appeared in the bill reports for NIH for FY 1984.

On December 3, 1983 a small advisory group, chaired by Dr. Lawrence E. Shulman, Director, Division of Arthritis, Musculoskeletal and Skin Diseases, NIADDK, met. The meeting was prompted because of the recent intensified Congressional interest in EB. As you recall NIADDK was directed to expand its research programs in EB.

The group met to discuss what mechanisms are most appropriate to encourage additional research in EB and EB-related diseases. The group consisted of NIH-supported investigators, NIADDK Skin Diseases Program staff and representatives of D.E.B.R.A. In keeping with the language in the bill reports in both houses, the discussions centered on three areas:

1. To strengthen and expand NIADDK's research programs on EB.
2. To explore the feasibility of a National Registry for EB patients.
3. To examine the need for Regional Centers for EB Research and Treatment.

1. How can NIADDK expand its research programs on EB?

It was generally agreed that because of the financial limitations of the Skin Diseases Program it would be fiscally irresponsible to publish a "Request for Applications" unless monies for such a commitment were made available from a source other than the already fully-commited general research funds for skin diseases. It was decided therefore that a "Program Announcement" without a specific financial commitment would be more appropriate. Language for this announcement would be coordinated by Dr. Eugene Bauer of Washington University.

.. It is important to point that a previous Program Announcement on Epidermolysis Bullosa issued by NIADDK in 1982 generated only one application, which was subsequently withdrawn.

Conclusions:

There is general agreement that because of the genetic factors, complexity and multi-disciplinary nature of EB, the research, support and management of this group of diseases must be shared among other Divisions, Bureaus and Institutes of the NIH, such as Child Health and Human Development, Dental, Eye, Cancer and General Medical Sciences.

It is my opinion, based on my personal and professional experience with EB, and by the members of D.E.B.R.A., including our scientific membership, that without stronger Congressional directives and specifically designated funds Federal efforts for increased research on EB and EB-related diseases will continue to be a slow and painful process.

As I see it the only recourse available to accelerate this process is to provide the NIH with funds that must be expended specifically on EB research. Once a critical mass of ongoing EB research has been established, I am convinced that the future for EB sufferers and their families will begin to appear more optimistic.

As always I look to you for your guidance and support.

Best regards,

Arlene Pessar

Arlene Pessar, R.N.
Executive Director

P.S. I attended the recent meeting of NIADDK interest groups in Bethesda. I was very impressed by your speech at our luncheon - especially your statement, "YOU CAN'T PUT HOPE ON HOLD!" I agree and the hope of EB patients and their families has been put on hold for over a hundred years!!! You can give us back this hope.

Ms. PESSAR. Good morning, Mr. Chairman, Senator Hatfield. It is an honor for us to be here this morning. We are grateful to have this opportunity to talk with you once again about epidermolysis bullosa, an incurable life threatening genetic disease which causes blistering, scarring, and destruction of the skin and mucous membranes.

This is Cal Larson. Cal is 23 years old and has lived with epidermolysis bullosa since his birth. My own son, Eric, is 13 and he also suffers from a severe form of EB.

When I walk into this room I feel as if I am among friends because, indeed, you have been very generous in your support of NIH. More important, the members of this committee and their staffs have been extremely concerned about the quality of life of those who suffer from this disease.

However, I hope after hearing my statement and reading my written testimony you will see that serious problems still exist and while additional Federal support is desperately needed in order to expand the knowledge and understanding of this complex group of disorders.

As you know, the research support for epidermolysis bullosa falls under the Skin Disease Program of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases.

Although the exact figures are not available for the Skin Disease Program, it is estimated that of the $462 million budgeted for this Institute in 1984 approximately $11 million will be used to support research on all skin diseases including the more common ones such as psoriasis and acne.

In December as a result of directives from this subcommittee an advisory group met to discuss how the Institute could best expand its research programs on EB. It was generally agreed that even though the Institute did receive an increase in 1984 the Skin Disease Program does not have sufficient funds to support new areas of research such as EB.

Unfortunately the picture for 1985 is even worse as the budget proposed would significantly force the further reduction in the pace of NIADDK research and the number of new grants funded by the Institute will be fewer than in 1984.

Today, the scientific climate for research on EB is ripe. New advances in technology are available which can be directly applied to this disease.

For example, the development of monoclonal antibody technology and advances in genetic research have an enormous impact on EB and other inherited diseases.

If scientists can synthesize insulin in human growth hormone and isolate the gene responsible for PKU, it is not so far fetched to believe that answers to EB can be discovered as well. I know the only real hope for my son, Cal, and the thousands of others who suffer from this terrible affliction depends on advances in basic research.

I also know that when scientists are looking for an area to work on they go where they know they will have a chance of getting funded.

I, therefore, conclude my statement today by making two requests. One, that appropriations for the Institute, NIADDK, be increased to at least $550 million; and two, that an additional $2 million be provided over the next 3 years to support new research on EB and related diseases.

Additional funding of this magnitude would only support a few new research grants during this period of time. I'm convinced, however, that once a critical mass of ongoing research has been established the future for EB sufferers and their families will begin to appear more optimistic.

We know these are trying economic times, but we also know that without this additional financial support research on EB will continue to be a slow and painful process. I would like to end the statement with a quote made by you, Senator Weicker, during a luncheon before the NIADDK coalition in February. You said, "You can't put hope on hold."

I pray you will remember this when you are making a final recommendation. Thank you.

I'd like to add one more thing. Senator Hatfield has introduced a resolution to declare a National EB Awareness Week, the week of November 24 through December 1. We are thankful to the Senator for this and we look forward to the celebration.

If some research would be started by the NIH we really would have something to celebrate. Thank you.

Senator WEICKER. Arlene, thank you very much. Before turning it over to Senator Hatfield, here, Cal, is there anything you'd like to go ahead and say? You're the fellow that's on the spot here.

Mr. LARSON. Yes; there are recognitions for other diseases like muscular dystrophy and so on. There really hasn't been that much on this disease and so there aren't many people who know about it.

I think before anything can really be done to help it needs to be gotten out into the open so that more people and organizations know about EB.

Senator WEICKER. Is this something that you've had since childhood?

Mr. LARSON. I was born with it. Everyone who is like me has been born with it.

Senator WEICKER. Can you go to school normally or do you have to study at home? Tell me about that.

Mr. LARSON. OK. I started going to school in sort of a mixed combination of ways in that I was having to stay in the area but with other handicapped kids who were not only physically handicapped, also mentally handicapped. I started out in elementary school.

By the time I got to junior high I was getting very tired and it was very hard for them to divide my needs with the other kids needs because of the problems involved. So I had to leave the school and try to find some other way of doing school work at home.

Senator WEICKER. How many persons like yourself are there in the United States with EB, do you know?

Ms. PESSAR. Nobody really knows. We estimate there may be as many as 35,000, 50,000 people, most of them living in isolation. The only time they come out is when they need medical attention.

It's a terrible social stigma. It's like leprosy. There is just a terrible ignorance problem.

Senator WEICKER. And you're asking in your statement that there be $2 million set toward research specifically in this area?

Ms. PESSAR. Yes; over a period of 3 years. Also, I have an additional statement.

Senator WEICKER. I want to let you know right now, Cal, I don't think you'll find any difficulty in this committee. When I hear the millions and billions that we're asked to throw out there in terms of death and destruction, I just don't understand——

Ms. PESSAR. Well, you're speaking to the wrong person.

Senator WEICKER [continuing]. The small amounts here to help people like Cal.

Senator Hatfield.

Senator HATFIELD. Thank you, Mr. Chairman.

First of all, I'd like to thank Cal Larson for coming forward to testify here today, and also his mother and father, Carl and Estelle Larson, for their great courage as people and desire for bringing forth her testimony for her work on D.E.B.R.A.

I think there are two things I'd like to emphasize. One is the lack of knowledge about this problem and why I introduced the resolution. I think out of these national awareness weeks we can inform a lot of people and get a better understanding of the need.

Second, the figures are of a wide range. I have heard between 5,000 and 10,000. Whatever number, it is an orphan type of malady which has been neglected for far too long. I am persuaded that even though I've only had five families in my State who have indicated this kind of a problem, we've been putting some real special emphasis on it at the Oregon Health Science University. Dr. Reynolds, you may know, has been doing some very concentrated effort in work on this.

Even if there were only 5.000, were only 1,000, the numbers are not significant except for the fact we are neglecting an area where we have a great responsibility. You will find no more sympathetic person than our chairman. He has led the battle for so many of these causes.

We will join with him and give full support to this program. I just want to tell you how appreciative I am for your coming.

Ms. PESSAR. We're very grateful to you also. Thank you.

Senator WEICKER. Thank you very much. Thank you, Cal.

STATEMENT OF RON SANTO, HONORARY MEMBER, BOARD OF DIRECTORS, JUVENILE DIABETES FOUNDATION INTERNATIONAL

Senator WEICKER. Ron Santo, honorary member of the board of directors, Juvenile Diabetes Foundation International. Ron, come right on up. I have had the privilege of being with Ron for a few minutes this morning in my office.

This would be a good point where I have to attend another meeting. Senator Rudman has agreed to take over the Chair at this juncture.

Let me tell you, this fellow is not only a great ballplayer, but a great tennis player. [Laughter.]

I think you'll find a very fine sympathetic ear in Senator Rudman. So, Ron, if you'll excuse me now Senator Rudman will take over.

Mr. SANTO. Thank you.

Senator RUDMAN [presiding]. Mr. Santo, if you'd like to proceed, we're pleased to have you here.

Mr. SANTO. Fine. Thank you. The JDF testimony has been submitted already.

PREPARED STATEMENT

Senator RUDMAN. We are going to put the entire testimony in the record of the hearing as you presented it; and present whatever you like in addition.

[The statement follows:]

STATEMENT OF RON SANTO

I am Ron Santo, a member of the Honorary Board of Directors and the Chicago chapter of the Juvenile Diabetes Foundation. I was a member of the Chicago Cubs and Chicago White Sox baseball organizations, and am now Vice President of Interpoint Corporation, a restaurant management company. I have been diabetic for 25 years. Today, I appear before you on behalf of the Juvenile Diabetes Foundation, our membership and their families in over 160 chapters throughout the United States.

You number among the distinguished men and women who made the appropriations decisions in recent years that created a new horizon for the diabetic. We can now live each day with a little less fear that we and our children will become blind, suffer heart disease, be afflicted with neurological disorders, or be sustained only by a kidney dialysis machine. We are indebted to you because you heard our call and responded by providing the leadership and fiscal support for a comprehensive diabetes research, training, prevention, education and control program -- a program which has become a model of governmental effectiveness and efficiency.

The mechanism for continuing the Federal onslaught on diabetes is in place: Research is conducted in practically every NIH institute. There are seven diabetes research and training centers and four diabetes-endocrinology research centers in operation. The Diabetes Data Group and the Diabetes Information Clearinghouse are performing the functions that you mandated. The Centers for Disease Control and 20 State health departments are jointly conducting a wide range of activities to improve the quality of life for the person with diabetes and reduce morbidity, mortality, and the costs of diabetes and its complications. Recognizing that diabetes afflicts almost 50%

of adults in some Indian tribes, the Indian Health Service is implementing a Model Diabetes Health Care Program to develop and evaluate effective and culturally acceptable methods to reduce the severity of the disease and its costs. The National Diabetes Advisory Board, a body of government officials, health care professionals, and consumer-advocates for the diabetic provides a coordinated focus for the plethora of Federal diabetes-related activities. And, in a most exciting development, NIH has commenced a two-year nationwide trial to determine whether precise blood sugar control can prevent, slow, or reverse the devastating complications of diabetes.

THE SUCCESS OF THE DIABETES PROGRAM

These programs are the spokes of the wheel. The hub of our program, and the activity which gives us hope for ours and our children's future is RESEARCH. This Committee has responded generously to our pleas for NIH support during the past decade. What have these precious dollars bought? Has your investment produced substantial dividends? Can we point to successes in the treatment of this Nation's diabetics? Do we have a reasonable basis for being optimistic about a cure and prevention of diabetes? The answer is a resounding YES -- in terms of prevention, treatment, and potential cure.

Last year, JDF catalogued the multitude of diabetes research breakthroughs funded by this Committee: the isolation of a diabetes-producing virus; the identification of genetic markers for diabetes; the importance of meticulous blood sugar control of the mother and the monitoring of the fetus to reduce the complications of the diabetic pregnancy; the development of the insulin pump; the creation of human insulin through recombinant DNA; and the use of photocoagulation to significantly reduce the risk of blindness from proliferative diabetic retinopathy. I have been undergoing this laser therapy for the past two years with positive results.

As a diabetic, one of the most exciting areas of diabetic research -- one which embodies the potential to dramatically improve the quality of life of the diabetic within the next couple of years -- is pancreatic islet cell transplantation. The islets contain the pancreas gland's insulin-producing beta cells. The successful transplantation of these cells into the diabetic may actually reverse diabetes in the body receiving the transplantation. Researchers have successfully transplanted clusters of the insulin-producing cells from one animal species to another. Moreover, beta cells from healthy rats transplanted into diabetic mice actually reversed the diabetes in the mice. At a recent meeting of the National Diabetes Advisory Board, Dr. Paul Lacey, a pioneer in this area stated, "Studies in rats have shown that isografts of islets will prevent, reverse, or arrest complications of diabetes involving the eyes, the kidneys and the autonomic nervous system of diabetic recipients." Scientists are overcoming problems of rejection of islet cells, the isolation of these cells from large animals and man, and purification of islet tissue. Members of the Committee, we are talking here of the potential for a cure.

With this good news -- developments which have resulted directly from your support of diabetes research at NIH -- we cannot permit ourselves to live with a false sense of security. Diabetes remains the third leading cause of death in the United States; the leading cause of new blindness; the cause of 50% of amputations of the foot and leg among adults; the cause of severe neurological disorders; the cause of a disproportionately high rate of infant mortality, congenital malformation, respiratory distress, prematurity, and other serious medical problems; a major risk factor for cardiovascular disease; and the cause of 20%-25% of all cases of kidney failure. The Federal government spends over $400 million per year supporting diabetics on dialysis machines -- two times NIH's allocation for research to eliminate this insidious disease once and for all.

The Administration has proposed for 1985 a budget request of $4.56 billion, a meager 2% increase over 1984 levels. Other witnesses appearing before this Committee have testified about the devastating impact of this budget on the entire effort of the biomedical research community. The Administration's proposed R&D increase for NIH of 2% compares unfavorably with the 22%, 14%, and 12% increases afforded the R&D budgets of the Department of Defense, the National Science Foundation, and the Environmental Protection Agency. We submit that this country's dividends from health research warrant an NIH investment of similar magnitude. Accordingly, the Juvenile Diabetes Foundation recommends that Congress appropriate $5.214 billion for NIH in FY 1985, as allocated on our appended recommendations.

Within this 16% increase, we recommend that Congress specifically allocate $550 million to the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases (NIADDKD). This Institute's programs would be unduly hampered by the Administration's budget. The number of new research grants funded would be 100 fewer than FY 1984 and about 80 fewer than the average number over the past 7 years. Only 28% of all research grant applications would be funded. Paylines would dip to 170 while applications were funded with scores up to 200 during the period 1978-84. Even to support these meager levels of research, NIADDKD would be required to reduce its payments on awards by 15% below approved rates and cut continuation grants by 8%. NIADDKD is the only Institute which would fund far fewer new grants under the FY 1985 budget proposal than in FY 1984. Moreover, the Institute would be able to support about 75 fewer research trainees than in 1984, thereby further depleting the corps of young clinical investigators on whom we are counting for a cure of diabetes.

A $550 million budget for NIADDKD would restore cutbacks in research grants, traineeships, career awards, and intraumural programs. The budget would also permit the Institute to support 37% of all approved research grants -- 3% lower than the 7-year average rate of award -- and to fund research grants to a payline of 190. Without this modest growth, this nation assumes the monumental risk of retarding the great progress that the biomedical research community has made in alleviating diabetes and its complications and dozens of other serious health problems as well.

The Centers for Disease Control Program has been severely hampered since its inception because of inadequate funds to fully support the important diabetes intervention projects. We concur with the recommendation of the National Diabetes Advisory Board that Congress appropriate $9 million for CDC's National Diabetes Control Program in FY 1985. Moreover, in light of the critical diabetes problem among American Indians, we also respectfully recommend that Congress provide $1.9 million in FY 1985 for the Indian Health Service to operate the model diabetes corps programs and to expand training and information dissemination activities to other Service units.

Millions of Americans have died and suffered the complications of diabetes since I was diagnosed 25 years ago. Then a cure for diabetes was a pipedream; it is now on the foreseeable horizon. Will we mitigate diabetes complications and indeed prevent and cure this insidious disease? Will Congress provide sufficient funds so that NIH can maintain research momentum and bring this nation's 10 million diabetics closer to their dream? We hope that you, the members of the Committee, will continue to exercise the vision and patience to ignore what might be politically expedient and continue to do what you know in your hearts is right.

Thank you for your attention.

JUVENILE DIABETES FOUNDATION

FY 1985
APPROPRIATIONS AND RECOMMENDATIONS
(in millions of $)

NATIONAL INSTITUTES OF HEALTH	FY 1984	(Diab. $)	Admin. 1985	(Diab. $)	JDF 1985
INSTITUTE					
National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases	462.6	(93.2)	475.3	(95.8)	550.5
National Heart, Lung, and Blood Institute	703.2	(17.8)	718.9	(18.2)	815.7
National Eye Institute	154.7	(23.0)	157.9	(23.5)	179.5
National Institute of Child Health and Human Development	275.2	(9.4)	280.2	(9.6)	319.2
National Institute of Neurological and Communicative Disorders and Stroke	335.2	(7.3)	344.6	(7.5)	388.8
National Institute of Allergy and Infectious Diseases	314.1	(5.9)	325.4	(6.3)	364.4
National Institute of Aging	114.9	(2.5)	117.4	(2.7)	133.4
National Institute of Dental Research	88.2	(2.3)	91.1	(2.5)	102.3
National Institute of General Medical Sciehces	415.6	(1.0)	423.9	(1.0)	482.1
National Institute of Environmental Health Sciences	179.8	(.1)	183.8	(.1)	208.6
Division of Research Resources	242.6	(17.8)	245.7	(18.0)	281.4
Other	1,119.2		1,202.4		1,388.0
TOTAL NIH	4,477.0	(181.1)	4,567.0	(185.9)	5,214.0
CENTERS FOR DISEASE CONTROL Diabetes Control Projects	6.0		6.0		9.0
INDIAN HEALTH SERVICE Control Projects	1.4		1.4		1.9

* Appropriations at this level would result in an increase of approximately 17% in diabetes research

Mr. SANTO. I would just like to present my feelings. I was diagnosed at 18 years old that I was a juvenile diabetic. I had just signed a professional contract with the Chicago Cubs.

I spent 15 years in the big leagues, 14 with the Cubs and 1 year with the White Sox. I have had diabetes for 25 years, going on my 26th year.

When I was diagnosed, the doctor told me there would be no cure. He told me I had to learn to live with it, understand it, and accept it. A lot of diabetics today have not done that.

I think I'm a minority in the fact that I've been very lucky. After 25 years, I think if you look at me you'll wonder, does this man look like he's a diabetic? Or what does a diabetic look like?

But it's a very serious disease. Without the help of NIH and your committee, we wouldn't be where we are today. When I say where we are today, what you have done is we're very close to a cure. I feel very definite about this.

I've had it for 25 years. I've been told always that we were within 5 to 10 years of a cure. Well, I really feel, since the Federal Government has come up with the moneys they have, that since then we have insulin pumps for brittle diabetics, we have the glucometer to check your blood sugar all the time, lasar technology.

Two years ago, I was diagnosed in my 23rd year with diabetes as having proliferative retinopathy, which is the No. 1 cause of blindness, is diabetes. I was given laser 2 years ago.

Thank God for laser because, without laser, within a matter of 5 years I would be blind. But because of the laser and the technology I'm in remission and I'm very thankful for that.

I feel very strong that Dr. Lacey, with the beta cells and eyelets transplants, has brought us very close to a cure. I don't think people realize that diabetes is the No. 1 cause of blindness, kidney failure, hardening of the arteries, neuropathy.

I have a walkathon in Chicago, a Ron Santo Walkathon. We raised in the last 5 years over $300,000. I had one person come up to me and say, "My sister died of diabetes." People don't realize how many people do die of diabetes.

I feel like in 25 years I've lived my expectancy of a juvenile diabetic. I feel I've been very fortunate. Within the next 5 years if we can find a cure I'm going to be very happy; but also for those many families that have kids that have to take that shot every day and that don't understand it.

But it's because of your committee that has done so much for us that I'm here to thank you and look forward to a little increase. At least a 16-percent increase is what we're looking for.

I would like to say one story quickly. When I first got into baseball every roommate I had I would tell that I was a diabetic. This one particular roommate, Glenn Becker who was a second baseman with the Chicago Cubs, I forgot to tell him.

We were in Cincinnati one day. That particular year I was hitting .312. Around June, he was hitting around .220. Well, I would get up in the morning, 8 o'clock in the morning, even when we had a night game, and I'd go into the bathroom.

In this particular bathroom we had a mirror. I would go in and give myself an injection. Well, he happened to be up and I didn't know it. He happened to see me give this injection.

That night I went 3 for 4; he went 0 for 4. [Laughter.]

We went to dinner after and he is sitting across, and he says, "Roomie, you're hitting .312, I'm hitting .220. What's that stuff you're taking?" [Laughter.]

When I told him that was insulin and I said I was a diabetic, he says, "Well, you don't look like a diabetic."

But today I can honestly say that people are more aware of diabetes. What your committee has done I'm just very thankful for. Thank you.

Senator RUDMAN. We thank you very much for taking the time and coming up here.

Mr. SANTO. Well, thank you.

Senator RUDMAN. Appreciate your testimony very much.

I wonder if my colleague from North Dakota would like to make the next introduction.

STATEMENT OF REED T. KELLER, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF MEDICINE, UNIVERSITY OF NORTH DAKOTA SCHOOL OF MEDICINE

PREPARED STATEMENT

Senator BURDICK. I certainly would. I would like to introduce at this time Dr. Keller. Dr. Keller is chairman of the Department of Medicine, University of North Dakota. I'm sure he'll have something valuable to say to this committee.

Dr. KELLER. Thank you, Senator Burdick. I'm glad to be here, Mr. Chairman.

[The statement follows:]

STATEMENT OF DR. REED T. KELLER

On behalf of the Coalition of Digestive Disease Organizations, comprised of nineteen National lay and professional organizations, and as a Member of the American Gastroenterological Association, I am pleased to have the opportunity to appear publicly before this Subcommittee, and especially my own Senator, Mark Andrews, from North Dakota.

Senator Andrews has cosponsored and introduced a joint resolution that designates May 20th through 26th as "National Digestive Disease Awareness Week". It is particularly significant that this designation be made, for during that week in May, the results of a National Harris Public Survey entitled "Public Perception of Digestive Health and Diseases" will be announced. The conclusions of this survey indicate the public suffers from a severe lack of knowledge and are victims of misinformation and myths surrounding digestive diseases. This is all the more significant in view of the fact that, according to the National Center for Health Statistics, digestive diseases are the leading cause of hospitalization and surgery in the United States.

The recently created National Digestive Disease Education Program (NDDEP), a coordinated effort of government (through the National Digestive Disease Education and Information Clearinghouse and the Education Subcommittee of the National Digestive Disease Advisory Board), lay and professional organizations, and the private sector has been designed to increase the awareness and understanding of digestive health and disease by the public, patients, and the health care community.

As a physician, I am well aware of the benefits that can be derived from an informed public. An educated public can:

1. take a more active role in the maintenance of digestive health;
2. assume a central role in their own health care;
3. recognize the signs that indicate potential disorders of the digestive system;

4. know when the assistance of a medical professional is necessary; and
5. comply with prescribed drug therapy, diet, and other treatment.

It is hoped that the National Digestive Disease Education Program, through its educational efforts, will cause a reduction in the incidence and impact of digestive diseases which, as I mentioned before, results in the number one cause of hospitalization and surgery in the United States.

Possibly foremost in our collective efforts to significantly reduce the alarming effects of digestive disease is the critical government investment of research. In this regard, my colleagues in clinical practice, the academia, and the research sciences, through their own affiliations, and with the recommendation of the National Digestive Disease Advisory Board, have agreed that the future of digestive disease research rests heavily in the continuation of basic research, and in the creation and growth of digestive disease research centers, which, like the diabetes and arthritis centers devoted to research, have proved to be a successful mechanism for fostering excellence in research and research training. The collection, availability, and use of clinical and research data, relative to diseases of the digestive system, is vital to the acceleration of progress. This has recently been facilitated by funding at NIADDKD for an Epidemiology Data System. We are hopeful that scientists and others will be able to effectively make use of this important, highly capable system.

The Coalition of Digestive Disease Organizations has several funding recommendations for the National Institutes of Health, and in particular, the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases. For fiscal year 1985 they are as follows:

A. Funding for the entire National Institutes of Health at $5.213 billion. This level of funding would modestly expand programs and arm the scientific and clinical research community with the resources necessary to continue current progress in studying all disease;

B. $550 million for the National Institute of Arthritis, Diabetes, Digestive, and Kidney Diseases. This increase would represent a restoration of cuts in new and non-competing research grants and for modest expansion in centers. Funding of $550 million would support the same number of trainees and career awards as in 1984, as well as allow funding of 37% of all approved research grants;

C. Continued funding, and expansion of the newly established Digestive Disease Centers of Excellence Program. Centers programs have proved to provide outstanding opportunities in research advances, and research training, and add another important dimension to existing research initiatives being performed;

D. Continued funding for the National Digestive Disease Advisory Board, which has always been extremely helpful and cooperative, the Digestive Disease Epidemiology Data Program, and the National Digestive Disease Education and Information Clearinghouse, that has recently become quite an invaluable program in our, and other National efforts to educate the public, and health care community about digestive diseases.

Mr. Chairman, this concludes my presentation. Please accept our thanks for the support your Subcommittee has demonstrated to the NIH programs concerning digestive diseases.

I am pleased to respond to any questions you may have.

Dr. KELLER. I'm particularly honored that we have two great Senators from North Dakota, Senator Burdick and Senator Andrews.

I'm here on behalf of the coalition of digestive disease organizations. This coalition consists of 19 national scientific and lay groups, all of whom exist for the one purpose of promoting our understanding and eventual cures of digestive diseases. I am particularly a member of the American Academy of Intestinal Associations.

Recently Senator Andrews cosponsored and introduced a joint resolution declaring the week of May 20 to 26 as Digestive Disease Awareness Week. During that week there will be a Lou Harris study called "Public Perceptions of Digestive Health and Disease" that I believe has been submitted in our written testimony.

There are a lot of interesting details. Just let me read the first sentence of the summary.

"Americans know and understand very little about digestive diseases and do not perceive digestive disorders as a serious health problem. They are victims of ignorance, victims of myths, misunderstandings."

Now, it's significant because digestive diseases are the No. 1 cause of hospitalizations and surgery in this country. So there is obviously an information gap.

Now, in an attempt to improve this gap there's an organization known as the National Digestive Disease Education Program. This has grown out of the National Digestive Disease Education and Information Clearinghouse as well as the education committee of the National Digestive Disease Advisory Board which sponsored this study.

This group, this educational group, works in concert with members of our coalition in order to promote the knowledge of your public and our patients on gastrointestinal disease.

Now, as an educator I'm quite aware of the impact that improving the educational level of our population will have. People will learn to recognize disease early; they will know when to appropriately seek medical intervention; and once under care they will be more compliant with our various diets, drugs, and treatment programs.

Now, as important as improving the knowledge of this country and our patients about the aspects of digestive disease, the real critical problem is that of continued research. All my colleagues in practice, all my colleagues in academia and research agree with the National Digestive Disease Advisory Board that it is key that research be continued.

We have been pleased with and we hope we will continue to get growing support for our digestive disease centers of excellence. There are a small number of these now. Like their counterparts in diabetes and arthritis we anticipate that we will have very fruitful yields in research.

The information exchange, both national and international, between these digestive disease centers has been enhanced by our epidemiology data system which is part of the NIADDK.

Now, on behalf of the coalition we have four specific recommendations for your consideration. No. 1, we'd like to see NIH targeted at

$5.213 billion. We feel that this level of funding would allow a modest expansion of all programs and growths of all centers, including digestive disease centers.

Specifically, our recommendation No. 2, we would like to see NIADDK be allocated $550 million. This increase would restore previous cuts and allow us to continue with ongoing programs, and allow a modest expansion of some centers.

We feel that distributive funding would support the same number of trainees, the same number of career clinical awards as we had in 1984, and would allow us to fund approximately 30 percent of already approved research grants.

No. 3, and very importantly, we hope to expand these newly established digestive disease centers. They have proved to be outstanding as vehicles for research and for the training of the next generation.

These centers not only will solve some of the research problems of today, but will train researchers in the next generation.

Last, we would hope you would continue funding the National Digestive Disease Advisory Board, the Digestive Disease Epidemiology Data Program, and the National Digestive Education Clearinghouse. For the last two entities, we would request $1 million.

We hope that all these programs can continue to bring about increased public awareness and increased research to lessen the impact of these very important diseases. I sincerely appreciate the opportunity to be here.

Senator RUDMAN. Well, thank you very much, Doctor. We're delighted to have you here.

Do you have any questions or comments?

Senator BURDICK. I want to thank you for your testimony this morning.

Dr. KELLER. Thank you.

STATEMENT OF ROBERT BOLAN, EXECUTIVE VICE PRESIDENT, AMERICAN DIABETES ASSOCIATION; REPRESENTING CHRISTOPHER M. SAUDEK

PREPARED STATEMENT

Senator RUDMAN. Our next witness will be Robert Bolan, executive vice president of the American Diabetes Association.

Good morning, Mr. Bolen.

Mr. BOLEN. Thank you, Mr. Chairman.

Senator RUDMAN. The entire statement will be printed in the record. I would appreciate your summarizing what you think are the most salient points of your testimony.

Mr. BOLEN. Thank you, Mr. Chairman.

I appreciate the opportunity to testify again before this subcommittee. I'm Robert Bolen, executive vice president of the American Diabetes Association; member of the board of directors; and a resident of Summit, NJ.

The written testimony, if I may, and a copy of the association's recommended legislative position, and a press release from the Department of Health and Human Services related to the clinical trial now underway in diabetes—if I could I'd like to enter each of these.

Senator RUDMAN. We will enter those in the record.

Mr. BOLEN. Thank you very much, sir.

[The information follows:]

STATEMENT OF ROBERT BOLEN

The American Diabetes Association (ADA) appreciates the opportunity to appear again before this Subcommittee. I am Christopher M. Saudek, M. D., Chairman of the Government Relations Committee of the American Diabetes Association.

We are at a point in the history of biomedical research that is extraordinary. Important developments in many fields of science are daily in evidence. Our capabilities in basic science and technology in the fields of medicine and biology are unsurpassed in the world. However, our leadership can be maintained only with continuing support for basic research, research training, clinical trials and applied medical research from the National Institutes of Health. We believe that this support must be at levels to assure not only stability in numbers of research grants but stable, continuing support for all high quality research. We must provide a program of research support sufficient to maintain good scientists in biomedical research and attract new scientists into the field. We also believe that whether the disease we are most concerned with personally or professionally is diabetes, heart disease, blindness or others, adequate support for the total NIH program is of paramount importance. That budget for FY 1985, as proposed by the President, is wholly inadequate in our opinion.

The NIH must be supported at least at levels of funding sufficient to support approximately 40% of research grants approved by NIH. This level of support would generally fund research grants only to scores of about 185; while higher by ten percent than the President's funding program, a 185 score is below the score to which grants have typically been funded in the past decade. The NIH budget must also support existing and new research grants and research centers at grant levels as approved by peer review. In the case of existing grants, there must be continued funding at prior commitment levels. Sadly, the Administration budget does not achieve these objectives but would cut existing and new research and center grants by substantial amounts averaging at least four percent and six percent but ranging to 15% in some instances. Only about 30% or slightly fewer of approved grants would be funded.

We join with more than 100 other health-related organizations in proposing a budget for NIH for FY 1985 of $5.2 billion, $647 million more than the President's budget.

National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDKD)

Within NIH, a number of Institutes have special interest for the ADA. About 50% of the $180 million spent this year on diabetes research by NIH is spent by the NIADDKD. This Institute is especially hard hit by the FY 1985 budget of the Administration, however. (Attached to my testimony is data from FY 1978 to FY 1985 showing the negative trends in the percentage of approved grants funded and priority scores of grants funded.) NIADDKD must reduce new research grants awarded by about 15% below approved rates, cut continuation research grants by eight percent and center grants by 19%. It is the only Institute funding far fewer new grants under the FY 1985 budget proposal than in FY 1984. In FY 1984, about 750 new grants will be funded but the President's FY 1985 budget, despite its commitment to stability in the number of new grants, will fund fewer than 650. Under the President's budget, only 28% of grants will be funded and no grant above a score of only 170 will be funded. This Institute will also be able to support, in total, about 75 fewer research trainees than in FY 1984 and center grants will be reduced by about ten percent.

Across-the-board reductions in grant payments may allow more grants to be funded, but reductions do not increase the amount of scientific research being performed. Instead, research projects are shortchanged, and the quality of science is reduced.

What is needed for NIADDKD? A $550 million budget for FY 1985 is needed. Such a budget would restore cuts in new and non-competing research grants of 15% and 8% and in centers of 10% It would support the same number of trainees and career awards as in FY 1984 and restore about $5 million of cuts in the intramural program which has been one of the stellar research enterprises at NIH. A $550 million budget would also allow the Institute to fund 37% of all approved research grants, (3% lower than the seven-year average rate of award) and to fund research grants to a payline of 190 (still 10 points below the seven year average).

A $550 million budget for FY 1985 would, in summary, restore the program to FY 1984 levels, and allow an additional $10 to $12 million dollars to support all grants with scores of up to 190. Without such modest real growth, important opportunities will be missed and our scientific effort will be eroded. This proposal also achieves the important objective of funding excellent research, that with scores of about 190. To do less will leave much excellent research unfunded and result in opportunities being lost or delayed.

Diabetes Research Activities and Achievements

What can this kind of support produce?

Let me provide you with some examples of the important activities of the NIH and NIADDKD in the diabetes field. A major clinical trial is now underway which will enable us to know the effectiveness of strict types of control of blood sugar on the complications of diabetes. It should be fully operational sometime in FY 1985 and it needs to be fully supported. This trial will provide us with an extraordinary capability of instructing health professionals on precisely how to manage diabetic care to assure the optimum results. As you know, DNA research has already produced much needed artifical insulin and the laser treatment has produced methods of reducing blindness and disability. A clinical trial in the Eye Institute is now testing the efficacy of the laser treatment in earlier stages of diabetic eye disorders. This research and the clinical trial on strict blood-sugar control are likely to create substantial savings in disability programs and lost tax revenue. Developments continue with respect to the use of the automatic insulin pump.

There are, in the words of NIH, "breakthrough" studies on transplantation of insulin-producing cells in animals. Not only does this promise to be a great advance for diabetics, but for immunology and organ transplantation generally. If perfected, transplants might provide a "cure" for diabetes.

The potential benefits of diabetes research are tremendous, both in the reduction of human suffering and the improvement in the quality of life for patients with diabetes. For example, if general application of today's treatment advances could reduce new cases of diabetes-related blindness by 20%, there would be a savings to federal agencies of at least $9 million a year in current disability payments and benefits. Reduction of all premature morbidity and mortality of diabetes by 20% would put $1.2 billion back into the economy. The risk of most diabetes-related complications associated with pregnancy alone can be significantly reduced today, potentially saving from $10,000 for each week of intensive care nursing for sick infants (or close to $20 million annually) to $1 million for the lifetime care of each severely handicapped infant. Another modest and realistic goal today is a ten percent reduction in amputations -- saving $22 million a year in direct hospital costs, much of which is now paid by federal agencies.

Diabetes research activity, while producing much already of benefit to diabetics and to the country in reduced disability, has recently been relatively supported at lesser rates than other programs in the Institute and throughout NIH. We would urge the Committee to generally reiterate its support for an ongoing NIH-wide diabetes research initiative with diabetes research to receive at least its proportionate share of increases for NIH.

CDC Diabetes Control Program:

We recommend a $10 million program in FY 1985 which is a $4 million increase over FY 1984. We recommend that funds for this program be specifically set aside in the appropriation for FY 1985. Presently, it is one of many chronic disease programs in the budget, and if money is to be assured for use in the diabetes control program of CDC, it needs to be specifically designated for such use.

The CDC has established Diabetes Control Program projects in 20 states. These programs are now yielding significant results in the important areas of community health care and education of diabetic people. The diabetes control program is one of grants to state health departments in states where diabetes is particularly prevalent and where the health department establishes programs to reduce the complications and morbidity associated with diabetes. These programs include professional education, training and education of patients in methods of self-care and management, and outreach programs. Already many of these state programs have demonstrated reductions in hospital stays for diabetics and surgery performed on diabetics.

A budget of $10 million is necessary to: (1) expand to $300,000 per state the existing programs, a level only 20% above the original commitment levels — this would allow the state programs to expand to other areas and activities; (2) establish at least five new programs in five new states.

HHS NEWS RELEASE

April 9, 1984

More than the 250 people with diabetes needed for a two-year, nationwide study to determine whether precise blood sugar (glucose) control can prevent, slow or reverse the devastating complications of diabetes have voluntarily enrolled in the study.

The study, the Diabetes Control and Complications Trial, is sponsored by the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases and three other institutes of the National Institutes of Health.

Twenty-one medical centers, a data coordinating center and five institutions that provide central laboratory or technical support are conducting the trials.

Diabetes, a disorder that interferes with the body's ability to use digested foods for energy, affects an estimated six million Americans; an additional five million individuals may have undetected diabetes. Between 300,000 and 500,000 Americans have insulin-dependent diabetes, the type studied in the Diabetes Control and Complications Trial.

Long-term complications of diabetes, caused by damage to blood vessels, can include blindness, heart disease, stroke and kidney disease. Damage to nerve tissue also occurs, resulting in chronic pain and loss of sensation which may lead to amputation of lower extremities.

The volunteers have met the medical eligibility requirements and agreed to accept random assignment to either of two types of treatment that will compare "standard" and "experimental" procedures.

The two-year trial will compare the two forms of treatment to determine whether they are safe and will produce a significant difference in the level of blood glucose control in patients; and whether the effects of treatment can be precisely and reliably measured using the types of biochemical and clinical methods outlined in the study.

The standard treatment will include one or two injections of insulin per day, a specialized meal plan, urine testing, an educational program and a routine checkup every three months.

The experimental treatment will include either insulin injections three or four times a day, or insulin given continuously using an insulin pump; a specialized meal plan; self monitoring of blood glucose levels; an education program; an initial hospital stay as treatment is begun; and checkups at least once a month.

If the results of the first two years of the trial demonstrate that a larger study is feasible, a seven to 10-year, full-scale clinical trial will be undertaken and additional volunteers will be recruited.

Baseline data--the clinical, biochemical and demographic information gathered on patients as they enter the study and before they begin treatment--will be presented at the meeting of the American Diabetes Association in June.

Other NIH institutes contributing to the study, include the National Institute of Neurological and Communicative Disorders and Stroke; the National Heart, Lung, and Blood Institute, and the Division of Research Resources. In addition, many commercial organizations have provided supplies, equipment and services.

DIABETES CONTROL AND COMPLICATIONS TRIAL CLINICAL CENTERS

Case Western Reserve University
Cleveland, OH

Children's Hospital of Philadelphia
University of Pennsylvania
Philadelphia, PA

Cornell University Medical College
New York, NY

Henry Ford Hospital
Detroit, MI

Joslin Diabetes Center, Inc.
Boston, MA

Massachusetts General Hospital
Boston, MA

Mayo Foundation
Rochester, MN

Medical University of South Carolina
Charleston, SC

St. Louis Park Medical Center
Research Foundation
Minneapolis, MN

University of Iowa
Iowa City, IA

University of Minnesota
Minneapolis, MN

University of Missouri at
Columbia
Columbia, MO

University of Pittsburgh
Pittsburgh, PA

University of Tennessee
Memphis, TN

University of Texas
Dallas, TX

University of Toronto
Toronto, Ontario, Canada

University of Washington
Seattle, WA

University of Western Ontario
London, Ontario, Canada

Vanderbilt University
Nashville, TN

Washington University
St. Louis, MO

Yale University
New Haven, CT

DCCT DATA COORDINATING CENTER

Biostatistics Center
George Washington University
Bethesda, MD

DCCT LABORATORIES AND TECHNICAL SUPPORT UNITS

Central Ophthalmologic Reading Unit
University of Wisconsin
Madison, WI

Central Hemoglobin A_{1c} Laboratory
Joslin Diabetes Center, Inc.
Boston, MA

Central Neurobehavioral Coding Unit
Western Psychiatric Institute and
Clinic
Pittsburgh, PA

Central Nutrition Coding Unit
University of Minnesota
Minneapolis, MN

Central Biochemistry Laboratory
University of Minnesota
Minneapolis, MN

Central Autonomic Coding Unit
University of Louisville
Louisville, KY

Central EKG Reading Unit
University of Minnesota
Minneapolis, MN

LEGISLATIVE POSITION: FISCAL YEAR 1985

SUMMARY

GENERAL POSITION ON HEALTH BUDGET

We recommend that in FY '85, federal discretionary health programs (those other than Medicare and Medicaid) be supported at levels that will at least enable them to maintain current FY 1984 levels of services and activities.

A. SPECIFIC BUDGET AND APPROPRIATIONS FOR FY '85

1. Appropriations for the National Institutes of Health for FY '85: $700 million over FY '84, for a total NIH budget of about $5.3 billion.
    a) Within the total NIH appropriations: An appropriation for NIADDKD for FY '85 of about $88 million over FY 1984, for a total budget of $550 million.
    b) For all other Institutes, a budget sufficient to permit research grants to be funded to scores of at least 190 and the same number of new projects, at least, as FY '84.
2. Centers for Disease Control, Diabetes Control Program Appropriations for FY '85: $10 million.
3. Indian Health Service Model Diabetes Care Program Appropriations for FY '85: $1.9 million.

B. SEPARATE INSTITUTE LEGISLATION AND OTHER AUTHORIZING LEGISLATION

If a separate Arthritis Institute is established, Congress is urged to add sufficient funds to the NIH budget in FY '85 specifically to support any new overhead costs.

We recommend the renewed authorization and continuation of the National Diabetes Advisory Board, the Diabetes Research and Training Center program and the research training program. These authorities are contained in H. R. 2350 as passed by the House and S. 773 as reported by the Senate Committee but not passed in the Senate.

C. JOINT RESOLUTION PROCLAIMING NOVEMBER AS DIABETES MONTH

LEGISLATIVE POSITIONS for the CURRENT YEAR
and
FISCAL YEAR 1985

GENERAL POSITION

Diabetes affects some 11 million people and this year about 600,000 new cases will be diagnosed. The disease is the fourth leading cause of death and its complications include many major disabling conditions such as blindness, heart disease, kidney disease, stroke and amputations. The federal government since about 1975 has played an active role in improving care for diabetics and in determining the causes of the disease. NIH research into the cause of the disease and its treatment is undertaken throughout NIH and about $180 million was expended in FY '84. About one-half of NIH research support is in NIADDKD but other sources of major research are NHLBI, NEI, DRR and the General Clinical Research Centers, NICHHD and NINCDS. Major developments have included laser treatment for blindness, and the use of implantable insulin pumps to control blood sugar. Besides research, the CDC supports a major health service program intended to improve diabetes care and to translate new research into improved care. The Indian Health Service also has a special program relating to diabetes.

Clearly, the role of the federal government is critical in improving the care of diabetes. The result is reduced mortality and morbidity from this very prevalent disease. The ADA urges continued federal effort in all federal health areas and urges spending in health programs generally which can maintain all federal public health service programs at least at FY '84 service levels.

SPECIFIC LEGISLATIVE POSITIONS

ADA Positions on Health Legislation for FY 1984 and FY 1985

A. Budget and Appropriations Recommendation for 1985:

1) NIH Budget for FY '85: An increase of about $700 million over FY '84 which is about a 15% increase.

The individual research grant is the core of the NIH program. During the five years ending with FY '83, the NIH was able to support about 5,200 new research grants each year. In FY 1979, nearly 6,000 new grants were funded while 4,800 to 5,300 new grants has been the norm since then. With fewer new grants recently, more and more good science is going unfunded. Grant applications are scored on a range of 100 which is perfect to 500. In FY '81 to FY '84, NIH was on the average unable to fund grants whose scores were 195 or higher whereas in FY '79 and FY '80 and prior years, grants were funded to scores of, on the average, 220 to 230. It is generally believed that a score of 225 is excellent science. In the past three fiscal years, only about one in every three approved research grants was funded whereas the rate of award was 45% or about one in two in FY '79 and FY '80 and prior years. In the current year, it is estimated by NIH that about 5,300 new research grants will be funded but the score at which NIH will stop funding grants, on the average, is estimated to be about 185 — the lowest level in many years.

We recommend that the NIH budget be sufficient to assure that all institutes are able to fund research with scores of at least 190 and to fund about 40% of approved grants. We believe that in three years, all institutes should be funding grants to scores of 200 and fund 45% of approved grants. These grants should be at about full cost as they were required to be by the FY '84 appropriation bill. Over 6,000 new grants are needed in FY '84 to support grants with 190 scores and an award rate of 40%. We also recommend that clinical trials, centers, intramural research and the Research Resources Program should be maintained at FY '84 program levels, which should include an inflation increase using the biomedical research inflator which is estimated to be about 11.6%. The training program should be expanded above FY '83, FY '84 levels if at all possible so that at least 10,000 new trainees are funded.

We estimate that an increase of about $700 million above FY '84 levels is necessary in FY '85 to achieve these goals. That is an increase of about 15% over FY '84 and a rate of increase comparable to other federal research budget proposals such as NSF, Defense and NASA.

The Administration budget for all federal research and development programs in FY 1985 is 14% above FY 1984 with the Defense Department, the V.A. and the National Science Foundation increases being 23%, 19% and 15%.

2) NIADDKD Budget: We recommend an increase of about $88 million bringing the budget to about $550 million.

This Institute has supported an average of about 730 new research grants over the past seven years. In FY '84, it will support about 756 new grants and in FY '83, it funded 770. However, only about one in three approved grants has been funded over the past four years. The FY '85 budget will support only 630 new grants, far less than the Institute's historical share of 5,000 new grants and its number of new grants in recent years. Also, grants over 190 have not been funded during the past three years. Grants will be funded in FY '84 to only scores of about 180. Much excellent science is going unfunded in this Institute.

We recommend that sufficient funds be budgeted to enable the Institute to fund grants at full cost to at least a score of 190 and an award rate of near 40%. We also recommend that existing clinical trials centers and other programs be continued at current services levels. The training program should be increased to support the FY 1984 number of trainees. An increase of about $88 million over FY '84 would be necessary to reach these levels.

3) Centers for Disease Control, Diabetes Control Program: We recommend a $10 million program in FY '85 which is a $4 million increase over FY '84. We recommend that funds for this program be specifically set aside in the appropriation for FY 1985.

The CDC has established Diabetes Control Program projects in 20 states. These programs are now yielding significant results in the important areas of community health care and education of diabetic people.

The diabetes control program is one of the grants to state health departments in states where diabetes is particularly prevalent and where the health department establishes programs to reduce the complications and morbidity associated with diabetes. These programs include professional education, training and education of patients in methods of self-care and management, and outreach programs. Already many of these state programs have demonstrated reductions in hospital stays for diabetics and surgery performed on diabetics. Diabetes is one of the four diseases producing the greatest number of hospital stays for Medicare beneficiaries. Savings in Medicare and Medicaid from this program are estimated to be substantial.

All of these programs should be continued and the information gained should be disseminated to other populations in states without such programs. A budget of $10 million is necessary to: (1) expand to $300,000 per state the existing programs, a level only 20% above the original commitment levels — this would allow the state programs to expand to other areas and activities; (2) establish at least five new programs in five new states.

4) Indian Health Service Model Diabetes Care Program Appropriation for FY 1985: $1.9 million. (This appropriation is part of the Appropriation Legislation for the Interior Department, not HHS and is dealt with by the Interior appropriations subcommittee.)

This budget represents a $500,000 increase over the current level, in order to strengthen currently existing but underfunded IHS clinics. The potential expansion of Model Diabetes Care Programs to other sites is put off for the present, to allow first the necessary funding of existing programs.

B. Authorization Legislation

1) Authorization Legislation: Separate Institute Legislation -- H. R. 2350 as passed by the House, S. 733 as reported by Committee.

In 1983 both the House and Senate Committees reported legislation creating a separate Institute of Arthritis, Musculoskeletal and Skin Diseases, thus leaving a Diabetes, Digestive and Kidney Diseses Institute. The House bill has been passed by the full House in a modified version. The Senate bill has not reached the Senate floor.

If such legislation is enacted in 1984, the funding for any additional overhead and administrative costs of creating the new Institutes should not be taken from research program funds. Vital diabetes research programs must not be jeopardized by supporting the overhead costs of new Institutes which we did not propose creating. We urge Congress to add sufficient earmarked funds to the NIH budget in FY 1985 specifically to support any new overhead costs.

2) Authorizing Legislation: Other Programs -- H. R. 2350 (passed by House), S. 733 (reported by Committee).

The same legislation creating the new Institutes reauthorizes all existing programs. We support the following extensions which are in both bills: We recommend that Congress extend authority for the National Diabetes Advisory Board and the Diabetes Research and Training Centers for five years. Authority for the continued operation of the National Diabetes Advisory Board, which has existed since passage of the National Diabetes Act in 1977, is of central importance to continuation of growth and coordination of the diabetes research effort. This Board has performed a crucial role in overseeing optimal use of the available funding for both basic and clinical research. The Diabetes Research and Training Centers, also a product of the National Diabetes Act, have proven to be very successful in advancing diabetes research and care. They have encouraged a multidisciplinary approach to diabetes, drawing excellent investigators from many areas of science into diabetes research. They have also promoted "translational" activities, bringing research findings to the bedside.

We also strongly recommend the speedy extension of the research training legislation. Provisions in both bills extend this Act. We favor the funding levels of the House bill, however.

C. Joint Resolution Proclaiming November as Diabetes Month

Such a proclamation was passed and signed into law by the President in 1982 and 1983. The proclamation has assisted greatly in increasing public awareness of diabetes and its impact. We would urge its enactment in 1984.

Mr. Bolen. As an overview the American Diabetes Association appreciates the excellent work already underway bringing us closer to the elimination of diabetes through research, health care delivery, through public awareness of the risks, all of which can be characterized as part of the Nation's health promotion and disease prevention activities. You've heard testimony from Dr. Field and from Dr. Santell of the work underway and the impact that it has on individuals like him. The work of associations contributes as well. The American Diabetes Association will do everything it can to foster continued increases and private sector successes. As examples of these over $4 million in direct research awards to over 100 scientists are awarded each year. An educational program was conducted just 2 weeks ago in which, for instance, Dr. Paul Bleisling of Dartmouth was one of the key members of the Boston site. It was attended by 20,000 physicians. We conducted an intensive program for some 3,000 scientists, specialists each year. Patient publications such as Diabetes Forecast magazine and Diabetes 1984 are received now by over 4 million patients four times a year, and in the case of Forecast, six times a year. International membership reaches to 50 countries, and I could go on and on. The association is the largest, most rapidly increasing voluntary health agency among any in the national health counsel. It was last year; it was the year before. And it has been, on a continuing basis over the last 5 years. And at the same time, it has low administrative costs. So we're very proud of these achievements.

But nevertheless, diabetes continues to devastate millions of Americans. I believe Dr. Field provided a number of statistics on the incidence of diabetes and the impact that it has, and I will not repeat those. Dealing with the number of Americans hospitalized and the cases of gangrene that require operations. Diabetes strikes women twice as often as men. It strikes black Americans also twice as frequently as white Americans. Hispanic Americans have diabetes approximately five times as frequently as other people in the population. So it strikes people that are not able to really afford the treatment.

Two people literally cripped with diabetes who passed away within the last year, and I think well-known examples, are Premier Andropov and Mr. Ray Kroc. These are well-reported cases of individuals who suffered from diabetes and who suffered from the complications of diabetes and were among the 300,000 people or so last year—well, not in the case of Premier Andropov, but in the case of Ray Kroc, of people who die of diabetes and their complications each year.

We get in the association's office approximately 50,000 calls or letters each year requesting help in the 700 or so places that people write in local communities or call in local communities. We receive over 1 million requests for where people can get information.

We need the help of Congress and the administration in order to move forward and to answer the questions and respond to these Americans.

In the research effort, we request that Congress maintain already established numbers of research awards, priority scores for successful applicants, and maintain the special centers and special studies now underway.

We think that the research and development activities through the National Institutes of Health in America should be on a par with any other research and development activities and that the support for the NIH budget should come to $5.3 billion for NIH and the NIADDK, $550 million.

In the case of health care delivery, we think that Congress—we recommend that Congress recognize the truly unique role of the diabetes control programs with the Centers for Disease Control. This is very possibly the best $6 million spent by the Congress for anything last year. And it is a program only operated in 20 States.

And as you saw in the papers, because of the announcement of the research done at NIH, and that's through CDC, for AIDS this morning. That is a program well known to you.

So we recommend that the fiscal year 1985 appropriation be $10 million to achieve a modest increase from 20 to 25 States.

And finally, in the area of public awareness, November has been the month of emphasis for public awareness for diabetes for many years, it is requested that you join with your colleagues and indicate support of a resolution for proclaiming November as national diabetes month, and we will again carry out all possible activities to bring this to people's attention. Research, health care delivery, and public awareness. And we certainly appreciate the great support and request that this support be continued in fiscal year 1985.

Senator RUDMAN. Thank you very much. I appreciate your testimony.

STATEMENT OF PAUL SHERLOCK, M.D., CHAIRMAN, NATIONAL DIGESTIVE DISEASES ADVISORY BOARD

PREPARED STATEMENT

Senator RUDMAN. Our next witness will be Dr. Paul Sherlock representing the National Digestive Diseases Advisory Board.

Welcome, Dr. Sherlock.

Dr. SHERLOCK. Thank you, Mr. Chairman.

Senator RUDMAN. We will take your statement, and your entire statement will be incorporated in the record, and you may proceed within the time allotted.

[The statement follows:]

STATEMENT OF DR. PAUL SHERLOCK

Mr. Chairman, I am Paul Sherlock, Chairman of the National Digestive Diseases Advisory Board. I am also Chairman of the Department of Medicine at Memorial Sloan-Kettering Cancer Center and Professor of Medicine at Cornell University Medical College. I speak to you today representing the National Digestive Diseases Advisory Board. All of the Board members and members of the digestive diseases field are most grateful to you and your colleagues for your continued support of biomedical research. However, we hope that you share with the Board our concern about the adverse impact of the proposed budget in 1985 on the progress on digestive disease research and on the implementation of the National Plan to Combat Digestive Diseases. It is our opinion that the proposed budget will have a major damaging effect.

In 1974 and 1975 Congress increased financial support to research in digestive diseases in response to a national conference which demonstrated the importance of digestive diseases as a national health problem. As a result of that support, there was an increase in the number of grants funded in digestive diseases. Since then there has been a yearly increase in the number of applications for new research grants reflecting a true growth of interest in the field.

In recognition of the growing importance of digestive diseases as a health problem Congress also added the name "Digestive Diseases" to an Institute, and called for the appointment of an Associate Director for Digestive Diseases. Further, in 1976 Congress established the National Commission on Digestive Diseases. In 1979 this Commission submitted a National Plan to Congress for this important group of diseases.

In its 1979 report to Congress, the National Commission on Digestive Diseases stated that:

> "Digestive Diseases constitute the third largest component of the total economic burden of illness in the United States, being outranked only by circulatory diseases and by the combined category of accidents, poisonings and violence."

The Commission made an intensive study and provided an extensive report on opportunities for research in digestive diseases.

The major recommendations of this Commission were: (1) to increase budgetary appropriations for digestive diseases research including multi-disciplinary Digestive Disease Centers, and (2) to establish data collecting groups to provide information on the incidence, prevalence, clinical course, and economic burden of these disorders and an educational clearinghouse, to increase public awareness and to provide information to patients and families regarding digestive diseases.

Last year, with the help of and an expression of interest by the Congress, digestive diseases research support received some real growth in budgetary allocations. However, the field still suffers from several years of budgetary neglect. This lack of bugetary support for growth in digestive diseases research is still a major cause for concern by the Board, especially in the light of some of the new promising opportunities for the prevention, treatment, and early diagnoses of these disabling disorders. These opportunities come from research advances made by NIH supported researchers and are reported in the publication "Research Advances and Opportunities". Some of the areas where significant advances have occurred include:

Topics (See attached report entitled: Research Advances, Opportunities, and Needs in Digestive Diseases)

1. Gastrointestinal Development
2. The Physiological Basis of Gastrointesinal Function
3. Smooth Muscle Disease and Motility
4. Gastrointestinal Regulatory Peptides
5. Prostaglandins
6. Immunology of the Gastrointestinal Tract
7. Nutrition
8. Infectious Diarrheal Diseases
9. Viral Hepatitis
10. Liver Detoxification
11. Liver Transplantation
12. Gallstone Disease

13. Gastrointestinal Precancerous Conditions
14. Gastrointestinal Endoscopy

With advances in these areas, there is now the opportunity to understand, clarify, and to bring effective clinical treatment to many Americans suffering from diseases of the digestive tract.

In addition to the identification of research advances and opportunities, the Board through its sub-committees is involved in the development of an algorithm using decision theory as applied to medical practice. This project is directed to reducing the costs associated with the medical surveillance of patients who, because they have precancerous conditions, are at risk of developing cancer of the colon. It is possible that this concept of decision theory may be extended and may aid in the management of patients with other digestive diseases.

The Board in cooperation with HCFA is also developing data concerned with establishing the incidence, prevalence, and costs associated with diseases of the digestive tract. The Board is also significantly involved with the development of a National Digestive Diseases Education Program. This program will utilize the resources of the private sector, voluntary health organizations, and government agencies to support a coordinated patient information and education health care program for digestive diseases for the public and health care professional. A report on these projects is available to you, members of your Committee, and to other members of Congress as part of the Second Annual Report of the Board.

Mr. Chairman, I wish now to discuss some of the budgetary facts concerning research activity in digestive diseases. The FY 85 budget proposed by the administration provides for a slight increase in total funding for NIADDK over the FY 84 funding level. Because of the inflation in biomedical costs and the increased costs associated with research grants, a number of drastic actions will be necessary to maintain research grant activity in NIADDK. Based on past experience the NIADDK anticipates that in FY 85 there will be over 300 new applications for new and competing regular research grants in digestive diseases. The number that will actually be funded is estimated to be less than 100, i.e., only 29% of the grants wil be funded. Only grants which receive a priority score of 170 or lower will be funded (the lower the score, the more meritorious the grant). The costs of all NIADDK new research grants will be cut by 15% in direct costs. Center grants are scheduled to be cut by 19% and the newly initiated Small Business Innovative Research Program may undergo similar budget reductions. These cuts are in addition to those normally suggested by the scientific study section which reviews a grant application for scientific merit. Those who have entered the field will certainly face discouragement in light of this proposed budget and in spite of Congress's previous successful efforts to stimulate research in digestive diseases, the number of new digestive disease research applications will certainly begin to fall off.

The Board recommends that increased funds be specifically designated for digestive diseases research, especially for regular research grants and centers. Otherwise, we believe that some established investigators will abandon their research efforts, and research teams which often have been developed over decades of effort and recently encouraged with Congressional support will be dissolved. When this occurs to established investigators talented new digestive disease investigators may decide not to pursue a career in research. Thus, the successful efforts to develop interest in this important field will be lost. With the withdrawal of prospective investigators it may take an entire generation to redevelop teams of investigators with the skills, interest, and resources required to conduct research in digestive diseases. This is particularly unfortunate since recent advances in sophisticated technologies that are so vital to the study of complex problems of digestive diseases now make it possible to pursue exciting opportunities which can lead to the prevention, cure, and to early diagnoses of digestive disorders. Thus, the long term consequences for health research manpower in the digestive diseases area are alarming, and the Board has the responsibility to advise Congress that the proposed budget for FY 85 will have serious adverse consequences on digestive diseases research.

The Board has carefully reviewed the recommendations of the Digestive Diseases Commission and the experience of Arthritis and Diabetes with their centers programs. It has concluded that certain research problems and opportunities may best be addressed by a variety of experts in basic and clinical science working together in the context of a center and so informed the Congress last year. The budget proposed for FY85 will stifle the initiatives undertaken by the NIADDK last year for the development of a Digestive Diseases Centers Program.

The Board strongly recommends that funds be allocated to digestive diseases for the continued development of a Digestive Diseases Centers Program comparable to those successfully created in Arthritis and Diabetes. Specifically, $8 million in FY85 be appropriated for this purpose.

The Board also recommends that the development of a Digestive Diseases Data System be continued to identify risk, prognostic, and diagnostic factors relevant to digestive diseases and to augment existing activities of the National Center for Health Care statistics and the Health Care Financing Administration.

The increased use of computers to record medical information offers a unique opportunity to accumulate precise and readily retrievable data on digestive diseases and disorders to obtain and record data in a standardized and accurate manner. It is particularly important to continue this newly initiated program before a multiplicity in uncoordinated systems develop because of the multitude of disorders which comprise digestive diseases. Endoscopic procedures offer a unique opportunity around around which to develop data system, because many are so new that systems of recording are still under development. Therefore this program development should continue to receive support.

The continuation of the National Digestive Diseases Clearinghouse is also recommended. Funding for this program and for the Digestive Diseases Data System program is recommended at $1.0 million in FY 85.

The Board supports appropriations of a minimum of 550 million dollars to the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases for FY 85 which will restore proposed reductions in new and competing grants, restore funding for Centers, and restore funds for intramural research. The Board recommends that funds be specifically designated to continue the development of the newly established program of Digestive Disease Centers such as those in Diabetes and Arthritis, and the Digestive Diseases Data Systems as those in Diabetes and Arthritis.

The Board recommends that it receive a proper level of funding in order to continue with its efforts to evaluate and to aid in the implementation of the National Plan to Combat Digestive Diseases.

We appreciate your support for digestive diseases, and appreciate all the efforts your Subcommittee has made to assure that the health of this nation is secured through enlightened legislation.

Thank you for the privilege to appear before you. I will be happy to respond to questions or comments.

Dr. SHERLOCK. Thank you, Mr. Chairman.

I am Paul Sherlock, chairman of the National Digestive Diseases Advisory Board. I am also chairman of the Department of Medicine at Memorial Sloan-Kettering Cancer Center.

I speak to you today representing the National Digestive Diseases Advisory Board. All of the board members and members of the digestive diseases field are most grateful to you and your colleagues for your continued support of biomedical research. However, we hope that you share with the board our concern about the adverse impact of the proposed fiscal year 1985 budget on the implementation of the national plan to combat digestive diseases, as reported in Congress in 1979, and which has recently been updated for the deliberations of our National Digestive Diseases Advisory Board. It is our opinion that the proposed 1985 budget will have a major damaging effect on newly enacted digestive disease research, recently supported by congressional actions to implement this plan.

The major recommendations of this plan were: (*1*) to increase budgetary appropriations for digestive disease research and to initiate a Digestive Disease Center Program, (*2*) to establish a Data Collecting Program, and (*3*) to establish an educational and informational clearinghouse.

Last year, with the help of and an expression of interest by Congress, digestive disease research support received some real growth in budgetary allocations. However, the field still suffers from years of budgetary neglect. This neglect for budgetary support for growth in digestive disease research is a major cause of concern by the Digestive Disease Advisory Board, especially in light of some of the new promising opportunities in digestive diseases. Some of these opportunities have been outlined by speakers this morning and have been addressed in my written testimony, as well as the Digestive Disease Board's updated report which were recently distributed to members of the subcommittee.

With proposed fiscal year 1985 budget increased costs associated with research necessitate a number of drastic actions to maintain research activities within the Institute known as the NIADDK. The proposed budget is bound to have a significant adverse factor on new investigators that might enter the field, as well as on established investigators which the young investigators look to as role models.

The board is distressed to learn that the proposed administration budget does not provide the opportunity for the continued growth of the newly instituted Digestive Disease Research Center as committed by the National Digestive Disease Advisory Board. The board strongly recommends that funds be allocated to digestive diseases, specifically to continue the Digestive Diseases Center Program. As per the amount recommended in the impending legislation, the board recommends $8 million in fiscal year 1985 for this purpose in order to sustain the 1984 activity and to allow for continued growth and momentum in this recently initiated program.

The board also recommends that the newly established digestive disease data system be expanded to include new areas of digestive disease research. At present, the system will include data related to the Liver Transplant Data Program. The continuation of the National Digestive Clearinghouse is also recommended, since this program has been beneficial to patients, to the public and to the primary physicians.

Funding for these two latter programs is recommended to be $1 million in fiscal year 1985. In order to restore the proposed reduction in new and competing grants and to continue the Digestive Diseases Program and restore funds for intramural research, the board also supports minimun appropriations of approximately $550 million for the NIADDK.

Mr. Chairman, we appreciate every effort this committee has made in the past through legislation to assure that the health of this Nation is secure and that human suffering from this vast array of diseases is reduced.

I thank you for this opportunity to testify and will be happy to answer any questions.

Senator RUDMAN. Thank you very much.

Dr. Sherlock, I was just looking at your statement here. I have a particular interest in something that's called to my attention on page 5. In the middle of page 5, your statement says that "Center grants are scheduled to be cut by 19 percent and the newly initiated Small Business Innovative Research Program may undergo similar budget reductions."

Why that reference? I was just curious?

Dr. SHERLOCK. Because with the proposed administration budget, in order for the NIADDK, as well as the other institutes to come into that particular amount, that amount would have to be cut from the budget.

Senator RUDMAN. That, of course, is a budget which the Small Business Committee and Senator Weicker and I worked on to get through the Congress, which was originally opposed by NIH, but I understand it's working rather well at NIH. And since that is calculated as a percentage of the total R&D money, that is extramural, not intramural in nature. It would only be the extramural research money that would result in any reduction.

So I was just wondering about that, but thank you very much. I appreciate your testimony. And we shall pay close attention to what you say.

Dr. SHERLOCK. Thank you very much.

STATEMENT OF ALBERT BRUCE KNAPP, M.D., POSTDOCTORAL RESEARCH FELLOW, BRIGHAM AND WOMEN'S HOSPITAL AND HARVARD MEDICAL SCHOOL, REPRESENTING THE DEAN THIEL FOUNDATION, CEDAR GROVE, NJ

PREPARED STATEMENT

Senator RUDMAN. Our next witness is Dr. Albert B. Knapp, representing the Dean Thiel Foundation.

Dr. Knapp, your entire statement will be put into the record as submitted.

[The statement follows:]

STATEMENT OF ALBERT BRUCE KNAPP

Mr. Chairman, distinguished Senators, ladies and gentlemen, thank you for giving me this opportunity to appear before you to share our concerns for the future of biomedical research and its dependency on the Postdoctoral Research Trainee Program.

Under the provisions of the Public Health Service Act passed by Congress in 1937, the National Institutes of Health [NIH] have supported a variety of postdoctoral training programs for biomedical researchers in academic research centers. The goal ostensibly has been to provide a framework where the young researcher could develop, expand, and improve his or her basic science training. This program has paid off handsomely in the form of a revolution in our biomedical knowledge. Millions of Americans, whose health is a primary concern for all of us, have benefited. This crucial investment in NIH training programs is shared by those of us whose careers are dedicated to investigating the complexities of the body, seeking cures for diseases that plague millions of Americans each year. We have an awesome responsibility and feel the pressures of time and resources in our eagerness to relieve the pain and suffering of children and adults as well.

Recent media attention given to liver transplants highlights two important facts. The miraculous advances being made through research and the tragic lack of effective, less costly treatments for many liver diseases which have forced thousands of patients to consider liver transplantation * * * their only hope for survival.

Liver diseases, as well as all digestive diseases, have been suffering from an identity crisis for years in spite of the fact that they are the leading cause of hospitalization and surgery in the United States today.

Ladies and gentlemen, we must increase the number of scientific investigators seeking solutions to these sadly neglected diseases. We all know this is a costly investment of time and dollars. I don't need to remind you, as parents, of the high cost of a college education; tuition, room and board. Medical school costs have skyrocketed, tripling since 1973. Those of us who have chosen research as our life's work have invested 4 years of college, 4 years of medical school, 3 years of internship and residency and must commit ourselves to 2 or 3 more years of postdoctoral research training. During the residency period, we attain some independence, receiving between $18,000 and $19,000 a year. However, most of us are still unable to begin to repay the average $26,000 student loans we have accumulated over the previous 8 years.

The choice of a research career at this point means dedicating 2 more years of postdoctoral research training. The current stipend paid by NIH during this period ranges from $14,040 to $19,716. I think you will agree that this is unrealistic compensation for talented, highly motivated scientists as this point in their careers. The combination of high debt and low NIH stipends often forces the brightest and most talented individuals to choose other paths. Tragically, many physicians with promising research careers are opting for lucrative private practices.

Another disturbing side effect for many of us who are in the Research Training Program, is the need to moonlight. The high debt and low NIH stipend phenomenon forces the trainee to pursue his or her career during the day and take on a second or third position at night and on weekends. Postdoctoral research training is not a 9 to 5 job but requires significant study at night and on weekends to master adequately the complex techniques and to keep current with new trends as well as to pursue promising results. Time spent moonlighting detracts from these important research endeavors. Ultimately, escalating debt in the face of insufficient income will make research training a financial impossibility for many exceptional physicians. Only those with adequate personal resources will be able to afford the luxury of a career in research.

We are also concerned about the proposed 5-percent increase in young investigator stipends, while maintaining the same dollar amount budgeted. This translates into fewer research training grants being awarded and ultimately less research being conducted.

The future of research in the United States depends heavily on a critical evaluation of the future potential of the research team being trained today. Can we afford to cut back on the pool of trainees and jeopardize the health and welfare of all Americans? In the long run we will all pay a high price—not just in our wallets but in our own personal health.

The Dean Thiel Foundation and the American Liver Foundation are dedicated to providing support for this and other research programs. Unfortunately, they are fighting an uphill battle to generate much sought after public support at a time when the human outcry heard on every TV channel and in every newspaper is for funds to pay for liver transplants.

We must continue our search for cures—and less costly treatments—to reduce not only the pain and suffering but also the economic burden to our Nation.

Thank you for giving me this opportunity to share my concerns with you.

Senator RUDMAN. And you may, within the time allocated, refer to any part of it or anything else you would like to refer to.

Dr. BRUCE. I also have another written statement, and I'd like that added afterward.

I'm Albert Knapp, a physician at the Brigham and Women's Hospital in Boston and I'm a gastroenterologist.

More importantly, I am what one would call a medical research researcher. And more importantly than that, I am a medical researcher in training. And what I'd like to do today is I'd like to share some of my concerns and some of the concerns of other people with the future of biomedical research and its dependency on the Postdoctoral Research Training Program.

Under the provisions of the Public Health Service Act passed by Congress in 1937, the National Institutes of Health have supported a variety of postdoctoral training programs for biomedical researchers and academic research centers. The goal, ostensibly, is to provide a framework where the researcher could develop, expand, and improve his or her basic science training. This program has paid off handsomely in the form of a revolution in our biomedical knowledge.

Millions of Americans, whose health is a primary concern for all of us, have benefited from these programs. This crucial investment in NIH training programs is shared by those of us whose careers are dedicated to investigating the complexities of the body, seeking cures for diseases that plague millions of Americans each year.

We, as a group, have an awesome responsibility and feel the pressures of time and resources in our eagerness to relieve the pain and suffering of children and adults, as well.

Recent media attention given to liver transplants highlights two important facts. First, the miraculous advances being made through research and, two, the tragic lack of effectiveness, costly treatments for liver diseases, which have cost thousands of patients to consider liver transplants as their only option. Liver disease, as all digestive diseases have, have been suffering from an identity crisis for years, despite the fact that they are the leading cost of hospitalization and surgery in the United States today.

Ladies and gentlemen, we must increase the number of scientific investigators seeking solutions to this sadly neglected disease. We all know this is a costly investment of time and dollars.

I don't need to remind you, as parents, of the high cost of a college tuition, room and board, et cetera. Medical schools, as well, have skyrocketed in cost.

What I would like to show here briefly is a graph of exhibit A—this is medical school costs. In brown, you see my alma mater, Columbia University. In red, the public medical school costs, and in green, private medical school costs. What I should direct your attention to is the literally tripling in real dollars seen between Columbia, for instance, in 1972 and 1984. As you can see, the takeoff for the private and public schools with the data we were able to get, only starts here, but the takeoff begins at that point. And you can see that it matches Columbia's.

Those of us who have chosen research as our life's work have invested 4 years of college, 4 years of medical school, 3 years of internship and residency, and must commit ourselves to 2 or 3 years of postdoctoral research training. During the residency period we receive some independence, receiving between $18,000 and $19,000 a year, and most of us are still unable to start repaying the average $26,000 to $27,000 in student loans we have accumulated over the past 8 years.

The choice of a research career at this point means dedicating 2 more years to postdoctoral research at the least. The current stipends paid for the National Institutes of Health range from $14,000 to $19,000. And I have listed them in exhibit E of my white paper.

I think that you will agree that this is unrealistic compensation for talented, highly motivated scientists at this point in their careers. The combination of this high debt and the low NIH stipend many times forces the most talented individuals to choose other paths. Tragically, many physicians with promising research careers are opting for lucrative private practices. Another disturbing side effect for many of us who went into the Research Training Program is the need to moonlight. High debt and low NIH stipend force the trainee to pursue his or her career during the day and take on a second and in many cases a third position over the weekends.

Postdoctoral research training is not a 9 to 5 job. It requires significant study at night and on the weekends to master adequately the complex techniques and to keep current with new trends. Time spent moonlighting detracts from these important research endeavors.

Ultimately, escalating debt, in the face of insufficient income, will make research training a financial impossibility for many of these physicians and many will be unable to afford the luxury of a career in research; let me close by the following. The future of research in the United States relies heavily on the critical evaluation of the future potential of the research team being trained today.

Can we afford to cut back on the pool of trainees and jeopardize the health and welfare of all Americans?

In the long run, we all pay a high price, not just in our wallets, but in our personal health.

The Dean Thiel Foundation and the American Liver Foundation are dedicated to providing support for this and other research programs. Unfortunately, they are fighting an uphill battle to generate much sought after public support at a time when the human outcry heard on every television channel and in every newspaper is for funds to pay for liver transplants.

We must continue our search for cures and less costly treatments to reduce not only the pain and suffering but also the economic burden to our Nation.

We must also support a $550 million budget for the NIDDK, and I really thank you for giving me this opportunity to share my concerns with you.

Senator RUDMAN. Thank you very much, Dr. Knapp. Considering the dedication of what you do, it is very interesting to have you come before us and tell us specifically the kind of problems. We're aware of those problems. This subcommittee is very aware of the problems of getting qualified people into research because they will not make what they could in private practice just to live.

Dr. KNAPP. I can give you just one example. I have a close friend, actually a classmate of mine from Columbia, who is being forced out of research; he is a brilliant researcher. The reason is, basically, that he has about $40,000 in loans. They go back to Yale College and Columbia Medical School. And many of those loans, as you well know——

Senator RUDMAN. I know all too well.

Dr. KNAPP. You know, you pay immediately, as soon as you graduate, and the interest on some of is 14 to 20 percent.

Senator RUDMAN. The person has no choice with the size of the stipend but to find a more lucrative way of living. I understand.

Dr. KNAPP. Thank you.

Senator RUDMAN. Thank you.

STATEMENT OF JOYCE WILLIG, COPRESIDENT, CONNECTICUT CHAPTER, AMERICAN LIVER FOUNDATION, REPRESENTING THE AMERICAN LIVER FOUNDATION, CEDAR GROVE, NJ

PREPARED STATEMENT

Senator RUDMAN. Our final witness of the morning, Joyce Willig, copresident of the Connecticut Chapter of the American Liver Foundation.

I'm sure our chairman would have liked to have greeted you, but every Tuesday, the chairmen of the various committees meet, and he just could not be present.

Ms. WILLIG. I can tell you that even as the committee dwindles before my eyes, it remains a more awesome experience than the transplant itself.

Senator RUDMAN. I would question that, but we're delighted to have you here. And you do have a statement and your entire statement will be in the record.

[The statement follows:]

STATEMENT OF JOYCE WILLIG

Good morning ladies and gentlemen. Don't be deceived by my outward calm. I'm a nervous wreck, but I wouldn't miss this opportunity for anything. I firmly believe I have a responsibility to tell my story, and that you have an equally important responsibility to listen. Individually there is little we can do to alleviate the indescribable suffering of chronic liver disease. Ahh, but collectively, as a strong, cohesive source of inspiration and information, there is much that we can do to galvanize a humanitarian government and public into action.

You may not be aware that this is the sixth day of Passover, the eight day festival celebrating the escape of the Jewish people from slavery into freedom. In the springtime of her life - on a Passover morning - this smiling rosy woman from Connecticut is here to tell you about her miraculous escape from the tyranny of a malevolent liver disease that enslaved her life for fourteen years.

I have been allowed four minutes to testify. Four minutes to tell you about the fear of dying, the joy of living and the damnable frustration of being a lady who caught the gold ring. Make no mistakes, ladies and gentlemen, I am overjoyed to be alive. I am living proof of God's handiwork - not so much what he has done for us - but what he has inspired us to do for each other. However, I am only one fortunate individual. One survivor out of 50,000 people who die each year of liver disease. I am alive but they continue to die and no one has an answer to their illness. There are more than 100 different kinds of liver diseases, most with no known cause and no known cure. Every day I speak to people who suffer from chronic liver disease. They look at me as though I am some kind of a Messiah and I am promising them the moon. Without your help all they are going to get are hailstones.

A liver transplant saved my life. I am eternally grateful but I remain one of only 600 liver transplant recipients in the entire country. What of the 50,000 others who won't receive a transplant? Unless you use your compassion and wisdom to fund the research that will end their pain and suffering they will die - and I will continue to be what I am - a woman who spends each day nurturing a double-edged sword - the incandescent joy of being alive and the gnawing guilt of not being able to save those who continue to die. There was a time when all I wanted was to live. Now I live to see others well.

Any disease is a misery. But how can I tell you how miserable it is to live with a disease for which there is so little understanding and carries with it such an unfair stigma? Recently the Wall Street Journal ran a front page article on the high cost of liver transplantation. A prominent physician was quoted as saying "No matter how outraged one might be, to a doctor the origin of the disease is irrelevant." The implication was that alcoholism is the primary cause of hepatic failure. How unjust and how untrue. There are 100 kinds of liver diseases, my friends, and only one derives from the bottle.

In 1972 I was diagnosed as having primary biliary cirrhosis, a slowly progressive, ultimately fatal liver disease. I am alive today because my life has been blessed with the endless love and skill of countless others who have joined their efforts not only for my benefit but for that of all mankind. I stand before you bearing testimony for the American Liver Foundation but truly I bear witness for the nobility and grace of all humanity.

I thank you for your concern and your attention. I am privileged to be here. If Robert Frost will allow me a quote, "The woods are long and dark and deep and I have miles to go before I sleep." Please take my hand, come with me, and help us find the answers to chronic liver disease.

I HAD A TRANSPLANT AND I'M WORTH EVERY PENNY

Hooray for the seals we're saving from annihilation
and an economy that's beating the high cost of inflation.
Hooray for our progress in the nuclear race.
We wouldn't want the Ruskies to catch us with egg on our face.
Hooray for the money we give to El Salvador.
It's always a pleasure to reinforce a war!
Hooray for the money we freely spend;
the planes and the rifles we gleefully send
to agressor and victor and rebels en mass,
as we arm with pleasure every faction and class.
But most of all, three cheers and a holler,
I had a transplant and it was worth every dollar.
I don't give a hoot how you fight and you yell.
There just ain't no price on feeling well.
Go right ahead; continue to discuss and bicker.
Staying alive sure beats getting sicker.
I'm well and I'm proud of my medical victory,
and I'm worth every penny that was spent on me.
I'll tell you my friend, and I mean it sincerely,
an investment return, the taxpayer's getting quite clearly.
I stand as a symbol of what science and humanity can do.
If you don't think that's worth the price, neighbor,
wait till catastrophic illness falls upon you!

Senator RUDMAN. You can present whatever you would like to. Just relax. It's a very relaxed atmosphere. We're delighted to have you here.

Ms. WILLIG. Before I begin, I would just like to say that I was very impressed with all of the testimony that I heard this morning, and I would hope that everybody here goes from strength to strength in their own endeavors.

Senator Rudman, a little over 2 years ago, this dimpled darling that is sitting so proudly and terrified in front of you was lying jaundiced, bloated, and dying in Yale New Haven Hospital, when my 15-year-old daughter pleaded with our family doctor to promise her that her mother would survive at least until she graduated, she was gently, but firmly told, that it most probably would not be possible.

I would like to tell you, Senator Rudman, that during this, our country's first National Organ Donor Week, April 22 through 28, and that through the love and humanity of an unknown family, this gift of life gave my life back to me. The improbable has become the possible. And I am very privileged and very honored to address you this morning—or this afternoon.

The motto of the State of Connecticut is Qui transdulit sustenant, which means, "He who transplanted still sustains."

As Connecticut's first adult liver transplant, and I've been that transplant for 2 years now. I would like you to know that I'm alive and well and sustained healthfully and happily in that State. It has been 2 shining years since my liver transplant--in that short span of time, tremendous strides have been made in liver transplantation. Fifteen hospitals across this Nation are now performing liver transplants with many more in the process—a very far cry from that bleak day in February 1982, when my husband was told, Mr. Willig, your wife is near death. There is one hospital in the United States performing liver transplants. With a liver transplant she may possibly live. Without a liver transplant, she will surely die.

Well, ladies and gentlemen, live, I did. And today I present myself to you as round, sound and rosy proof of the viability of liver transplantation.

Liver transplants, however, Senator Rudman, are a final and traumatic resort. They are not, by any means, the answer to the cause and cure of the over 100 liver diseases that by 1985 are predicted to be our Nation's third-ranking killer of men, women, and children.

A liver transplant was my personal blessing and it is, indeed, one of the major medical achievements of this century, but only a little bitty handful of the 50,000 Americans who die annually of chronic liver disease will receive a transplant.

And that, ladies and gentlemen, is the catch-22 of my miraculous rebirth.

You have allowed me 4 minutes to testify. That's 4 minutes to tell you as quickly as possible about the fear of dying, the joy of living, and the daily frustration of being 1 of only 600 liver transplants to catch the elusive brass ring.

I am overjoyed to be alive, but I am one victor out of thousands of people in liver disease who fight an ongoing battle to make it day by day.

I am an active, healthy live-it-up wife and mother, and they are debilitated and they are dying, and no one knows the answer to the cause and cure of their liver problem.

Unless you use your compassion and wisdom to fund the Federal research to stop their suffering, unless you come to grips with this national health crisis, and unless we join forces to fight liver disease, thousands of chronically ill adults and children will surely continue to a slow and agonizing death.

And God knows, I know. I've been there. Only instead of the unhappy ending many of you may have read about in the Washington Post yesterday, I am a bright and shining new beginning.

So much needs to be done to educate the public about the liver, and I would wonder if many of you seated here today know where your liver is or what it does, or that it performs 500 vital functions vital to life, or that contrary to public opinion, most liver diseases do not derive from a bottle. Alcoholism is a nasty stigma that is so erroneously associated with liver disease.

Gentlemen and ladies, I am smiling from God's handiwork. My rebirth represents not just what He has done for us, but what He has inspired us to do for each other.

I am wonderfully alive today, because my life has been cradled in the endless love of family and friends and by the love, skill, and medical genius of countless others.

I sit before you bearing testimony for the American Liver Foundation, but truly, in my heart, I believe I bear witness to the nobility and grace of all humanity.

I thank you with all of my heart for allowing me to present my testimony this afternoon.

And if Robert Frost will allow me to close with a quote—"The woods are long and dark and deep" and although I occasionally worry about rejection—"I have miles to go before I sleep."

And I ask you to come take my hand, walk with me, and together help us find the answers to chronic liver disease.

And I would like you to know that in June, both of her parents will be alive to see their daughter graduate with honors from high school.

Thank you very much.

Senator RUDMAN. Ms. Willig, thank you very much and thank you for very graphic testimony.

I can assure you that the members of this subcommittee are very dedicated to the kind of funding efforts that are necessary to try to achieve the kind of solutions that will make those thousands of Americans live long and fruitful lives.

This is only one of a whole range of medical problems that the NIH deals with which are in need of solution.

The people from the American Diabetes Association, of course, it's been an ongoing battle for years, which hopefully, now we're getting closer to.

And also, thank you for finishing your testimony with, obviously, my favorite poet, from New Hampshire.

Ms. WILLIG. Well, I want to thank you. I realize all the concerns that come before you, but I am so grateful for all of the progress and all the publicity and all of the joy that I've had from my own rebirth.

I still realize that when I became ill, no one really knew anything about anyone coming down with liver disease. I was a rarity. My parents thought that I had really imbibed during my college years.

I would appreciate it if more public awareness and knowledge could be made for liver disease.

ADDITIONAL PREPARED STATEMENTS

Senator RUDMAN. We thank you very much for being here.

Dr. Charles A. Rockwood, Jr., president of the American Academy of Orthopaedic Surgeons was not able to be present, but he has submitted testimony which will be made a part of the record.

We also have received testimony from Dr. and Mrs. Francis E. Wanat on behalf of the Dystrophic Epidermolysis Bullosa Research Association of America, which will be made part of the record. They were not able to be present today.

These statements along with other statements submitted for the record on appropriations for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases.

[The statements follow:]

STATEMENT OF DR. CHARLES A. ROCKWOOD, JR., PRESIDENT, AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

Mr. Chairman and members of the Committee, I am Charles Rockwood, M.D., Chairman of the Department of Orthopaedic Surgery at the University of Texas Medical School in San Antonio and the President of the American Academy of Orthopaedic Surgeons.

I am pleased to appear before you today to present the Academy's position on the need for continued and, if possible, expanded funding of research on the musculoskeletal system.

The musculoskeletal system is a major system of the body, involving those anatomic elements of structural support essential to the function of the body as a whole. This includes, for example, bones, joints, muscles, ligaments, and tendons. Research on the diseases and disorders of the musculoskeletal system is supported primarily by the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases through its Division of Arthritis, Musculoskeletal and Skin Diseases; however, smaller and more targeted programs are also supported by the National Institute on Aging and the National Institute of Handicapped Research.

Health, as Emerson said, is the "first wealth". Unfortunately for many Americans good health is not a reality. For example, over 36 million Americans are crippled or incapacited because of musculoskeletal conditions. I am referring to diseases and disorders such as:

- Arthritis, which is the leading cause of restriction of mobility;

- Joint disorders, which affect more than 15 percent of our population;

- Birth defects and inherited disorders which often lead to permanent handicaps, and a decreased life expectancy; and

- Hip and spine fractures and osteoporosis, which are common in our elderly population; and which account for a substantial cost to the Medicare program.

Musculoskeletal diseases, while not usually fatal, are among the most common causes of pain, disability, and disfigurement. In addition to the toll they exact in terms of human suffering, the economic impact of these disorders ranges into the billions of dollars each year for medical cost and lost productivity.

The investment of government funds in biomedical research over the past two decades has resulted in a substantial payoff to the taxpayer, and more importantly to those individuals afflicted with musculoskeletal diseases. The following are but a few of the more recent advances directed toward the prevention and treatment of musculoskeletal diseases:

- Bone Fracture and Healing. Approximately 5 percent of all bone fractures never reunite and heal normally. Studies have shown that electrical stimulation by either direct current or pulsing electromagnetic fields is an extremely valuable form of treatment in nonunion fractures resistant to other forms of therapy (such as bone grafts and other surgical fixation procedures). For this therapy, a snug plaster cast is applied to immobilize the affected bone, then Teflon-coated wire electrodes are inserted through the skin into the nonunion area. The wires are connected to an external power source and treatment is applied at home. Though the precise mechanism of action of local electrical stimulation therapy is unknown, it appears that cell behavior at the fracture site is modified so that, in the cartilage in the nonunion area, the process of calcification, vascularization, and replacement by bone is enhanced and accelerated.

The latest research in this area in laboratory animals involves "capacitive coupling," in which the electric energy is produced by charged plates applied to opposing sides of the area to be stimulated. In animals this method has proven more efficient for delivering stimulation to the nonunion site, and it may permit enhanced bone healing in difficult-access sites such as the hip and spine. Investigators are now pursuing additional studies, applying electrical stimulation techniques to other bone diseases, such as osteoporosis and osteogenesis imperfecta, and are attempting to promote bone growth into porous implant materials to overcome problems of loosening in total joint replacement.

- Osteoporosis. Past research has indicated that treatment regimens that include sodium fluoride may be effective in reducing the rate of bone fracture in postmenopausal women with osteoporosis. A recent clinical investigation systemically studied the effect of this therapy on the rate of vertebral fractures in a large group of postmenopausal women. Patients in the study received sodium fluoride therapy with or without conventional therapeutic agents such as calcium, estrogen, and vitamin D; after 1 year of therapy, vertebral fracture rates in the treated patients were reduced. Overall, 60 percent of patients treated with sodium fluoride showed increased vertebral bone mass on x-ray, and these patients had approximately one-seventh the fracture rate of other patients. The results of this investigation also showed that the most effective therapy was a combination of sodium fluoride, calcium, and estrogen. Researchers believe that patients who did not respond to fluoride treatment may have an intrinsic abnormality of osteoblast function that prevents the stimulation of bone formation above certain levels. Nevertheless, the beneficial outcome for the majority of patients in this study provides a basis for optimism about the effectiveness of fluoride therapy in combination with other available agents for the prevention of fractures in postmenopausal osteoporosis.

- Disease Diagnostics. A number of bone diseases such as osteoporosis and osteopetrosis result in alterations of bone density and subsequently affect bone strength. Recent significant advances in measuring bone density noninvasively have eliminated the need for performing bone biopsies to diagnose or monitor the progression of these conditions. A process called dual photon absorptiometry provides accurate measurement of bone mineral content, while computerized tomography (CT), a highly sophisticated x-ray technology, can produce accurate pictures of cross sections of bone. The use of dual energy modes in both of these techniques enhances the investigator's ability to discriminate between different bone components, such as mineral and marrow fat content, and therefore improves the accuracy of measurements. Other techniques -- neutron activation and Compton methods -- can be used to measure changes in calcium levels in addition to radiation scattering caused by localized areas of very dense bone. The development of these techniques is a significant advancement in our ability to diagnose and monitor many types of bone disease without exposing patients to the risks and trauma of surgery for biopsy purposes.

- Exercise Physiology. Basic research with animals has defined patterns of control occurring when muscles are tense or relaxed. So-called fast or slow muscle fibers respond differently to given training exercises. Physical training programs must include a variety of quick-motion, strength, and endurance exercises to accommodate both muscle types and to derive the benefits of exercise in terms of increased aerobic capacity and energy-producing activity. Studies have shown that fast muscle fibers have poor aerobic capacity and recover slowly from excessive work. Training can produce moderate improvement in these conditions.

Investigations of muscle activity and joint forces in athletic activity have shown that active muscle force is required to prevent injury from falls. These results show that, contrary to earlier belief, relaxing during a fall may increase the chance of injury.

These advances have contributed toward restoring people to productive life, improving the overall quality of life, and equally important, reducing the length of hospitalization and time spent in nursing homes due to musculoskeletal problems.

Although we have learned much about these diseases and we have substantially improved our treatment programs, we must continue our research in order to ultimately undertake prevention programs. It is only through prevention that we can give "Health as the First Wealth" to our society.

There are a number of promising areas of musculoskeletal research which, with continued funding, will contribute to earlier detection, better treatment, and hopefully prevention. For example,

- Osteoarthritis. While several theories on the etiology of osteoarthritis have been proposed, there is not yet a clear understanding of the pathogenesis of the disease. In osteoarthritis, the distribution and shape of collagen fibrils in cartilage are significantly altered. A crucial problem appears to be the poor ability of cartilage to repair itself. One possible explanation of this defect is that fibrin (protein formed during clotting) does not appear to adhere to cartilage cells because of a shielding effect of cartilage proteoglycans (carbohydrate-containing proteins).

In an animal model of cartilage defect repair, it has been shown that, during repair processes in osteoarthritis, type I cartilage is formed instead of the type II cartilage produced in normal joints. Investigations such as these on osteoarthritis and cartilage repair can be enhanced in the future through the use of recent improvements in tissue culture technology.

- Improvement in Artificial Joint Replacement. Total joint replacement means replacing damaged joint components with metal and plastic devices which are anchored to surrounding bone by cement; successful results are obtained in a very high percentage of patients. Some problems remain to be solved, however, particularly with regard to long-term use of prosthetic devices. Failure of total joint replacement can usually be traced to postoperative complications such as deep infection or thromboembolism (blood vessel obstruction), or to mechanical failure, such as loosening of the device from the surrounding bone. While improved bone cement or cementing techniques may alleviate somewhat the problem of loosening, a more permanent attachment permitting ingrowth of bone into the prosthesis may prove more effective. Researchers are now experimenting with porous coatings or special surface finishing that can be applied to existing metallic implants to allow bone ingrowth and strengthen the bond between the bone and the implant. Other investigators are pursuing studies to determine the cause and progression of deep infection and thromboembolitic complications as well. Continued research directed to overcoming these problems, and utilizing recent advances in areas such as gait analysis to evaluate the effects of treatment, will help to ensure maximum functional capacity of artificial joints for use over longer periods of time.

- Bone and Cartilage Allotransplantation. Allotransplantation of bone and cartilage is most frequently used in limb-sparing operations for tumors. After removal of a tumor, the resulting bone and cartilage defect is often too large to be replaced by a graft from another site in the same patient. However, the missing bone and joint surfaces can usually be replaced with an allograft from a donor cadaver. Present methods of allograft preservation and immunologic protection allow successful transplantation in most cases, but further research is needed to understand cases of host reaction to the transplanted tissue. In addition, more studies of freezing, thawing, and chemical preservation of tissue are required. A better understanding of immune phenomena in bone and cartilage, improved techniques for handling donor tissue, and advances in microvascular surgical technique will have important clinical applications in the future, not only for reconstruction of limbs, but also for transplantation in growing children with injured or diseased bones and joints.

- Treatment of Metabolic Bone Disorders. Greater knowledge of the basic mechanisms that regulate bone metabolism has led to improved therapy in metabolic bone diseases such as osteoporosis, Paget's disease, and several osteodystrophies. Basic research on resorption, formation, and the effects of hormones in normal bone turnover led to the finding that fluoride, in combination with calcium and estrogen supplementation, may be an effective therapy in the treatment of osteoporosis. Furthermore, such studies have shown that calcitonin and diphosphonates greatly alleviate the pain and misshapen bones that result from Paget's disease. Metabolic studies on the role of vitamin D in bone formation have also led to the isolation of new metabolites which, in combination with other agents such as phosphate, are being tested in the treatment of various types of osteodystrophy. Building on the knowledge gained from past investigations of basic regulatory mechanisms in normal bone, researchers will be able to pursue new studies, seeking better therapies for bone diseases resulting from altered metabolism.

- Mechanical Stresses and Bone Remodeling. Classically, it has been thought that normal and abnormal bone remodeling (resorption and formation) permit the development of bone structure best suited to resist whatever forces may be acting upon the skeleton. In ongoing studies, however, investigators are seeking more comprehensive theories to explain observed bone growth patterns. A recently developed research model of bone enables scientists to apply various loads to bone to examine the effects of different forces and levels of stress on remodeling. In preliminary studies, it has been shown that low levels of stress are associated with bone resorption, while moderate stress leads to bone formation. At high stress levels, resorption predominates again. Using such models, researchers will be able to modify existing theories of bone remodeling in response to mechanical stresses and to examine the effects of stress during growth.

As our population gets older, and the demographic data shows that the over 65 population will increase by 30 percent by the year 2000, it will bring with it a myriad of chronic and disabling disorders. A greater demand for health services, medications, devices, hospitalization and nursing home beds will accompany the graying of America. This, as all of you know, will place an enormous burden on the Medicare program. Today's problems of cost containment will appear insignificant when compared to the problems we will face in the 1990's, unless we take the necessary steps now to provide for an adequate investment in all aspects of biomedical research -- basic, applied, training and technology transfer.

Unfortunately, the proposed 1985 budget falls far short of its mark. In fact it doesn't even meet the cost of inflation.

Mr. Chairman and members of the Committee, we fully appreciate the difficult fiscal conditions under which you are operating, but we believe that in spite of these constraints, the government must provide for the sound health of its citizens today and into the future.

It is with this in mind that we respectfully urge this Committee to provide $550 million for the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases in 1985.

On behalf of the 11,000 members of the American Academy of Orthopaedic Surgeons, I want to thank you for your past interest and support of biomedical research and for giving me this opportunity to testify before you today.

I will be happy to answer any questions.

Summary of Recommendations - 1985 Budget

• National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases	$550,000,000
• National Institute on Aging	$130,000,000
• National Institute of Handicapped Research	$ 35,000,000

STATEMENT OF DR. AND MRS. FRANCIS E. WANAT, DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Our son, Edward, died on March 5, 1984 after eleven months of continuous illness due to Epidermolysis Bullosa (EB).

We write this statement still suffering emotionally and the futility of trying to solve his problems.

Edward's problems began at birth. He was three weeks premature and had blisters on his body at birth. He also had an extremely rare complication of EB known as pyloric atresia, where there is no outlet to the stomach. Major reconstructive surgery was necessary to survive and this was performed at five days of age. During hospitalization many blisters developed on his skin and inside his mouth which prevented breast feeding and limited bottle feeding. The feeding difficulties and malnutrition continued throughout the rest of his life.

After discharge from the hospital at three weeks, we tried to locate specialists who could diagnose Edward's type of EB. We also needed specialists to help diagnose the cause of his persistent daily "colic-like" pain. Although we are both health professionals, physician and nurse, with many resources available to us, we were unable to find the help we needed. Well trained, board certified, specialists in dermatology, pediatrics and gastroenterology were unable to make an accurate diagnosis. The skill and knowledge of the doctors was frightfully limited in regard to EB. We were told Edward had a mild form of EB and his improving skin lulled us into a false sense of security. Meanwhile the EB was silently destroying his larynx, bladder, and gastrointestinal tract. His daily pain became more severe, but we were told again, and again that it was colic and not EB.

At eight months of age, because of increasing pain, Edward had further evaluation. It revealed problems with the bladder, and kidneys. He was rushed to Columbis Presbyterian Babies Hospital in New York City for treatment of complete urinary obstruction. The pediatric urologists at that major medical center had no experience with EB. A medical literature search found two reported cases on urologic obstructions in children - both children died. Pediatric anesthesiologists, unfamiliar with EB, lulled the clinical experience and attempted to assist the urologists with a cystoscopic examination prior to surgery. Although the medical literature states that it is safe to use tracheal intubation during anesthesia in children with EB, Edward was not intubated during anesthesia. Catastrophe ensued. Edward had a respiratory arrest and his airway could not be kept open. He suffered massive brain damage. Our bright, normally developing child became a rag doll. He could not see, or smile, or make soft noises. His body was limp. He could not hold up his head.

Surgery peformed while he was in coma corrected the bladder damage caused by the EB, however, no amount of help or surgery could ever repair his damaged brain.

Six weeks later we were able to bring him home - alive, but desperately and terminally ill. When his condition stabilized slightly, we brought Edward to Dr. Eugene Bauer at the Washington University Medical Center in St. Louis, MO -- the only true EB center in the United States. Here, the physicians, nurses, and para-professionals had experience with EB. For the first time we received, not only understanding, but education regarding EB and the genetic implications for the rest of our family. This type of help must be available at more centers in the United States. Correct diagnosis and a plan of care is essential to help families and patients deal with this dread disease.

The help we received at Washington University Medical Center was too late to help our beloved Edward. He died two days after returning home. His suffering has ended - ours continues. More important, the living, and future children with EB have no hope without more research and care. This is not just a skin disease, but a complicated multi system genetic disease, and it needs a multi-disciple research approach to solve its riddle.

Legislative support for research and separate funding is desperately needed. We are counting on your help.

Thank you.

STATEMENT OF ANN KONE, EXECUTIVE DIRECTOR, PAGET'S DISEASE FOUNDATION

Thank you for the opportunity to present the viewpoint of the Paget's Disease Foundation on appropriations for the National Institute of Arthritis, Diabetes, & Digestive & Kidney Diseases (NIADDK).

The Foundation is a national organization and the sole spokesman for the sufferers of Paget's disease of bone, one of the numerous chronic and disabling diseases investigated under the programs of the NIADDK. We believe that the NIADDK, and all of the National Institutes of Health (NIH), must continue to have a strong level of financial support for the future well-being of today's -- and tomorrow's -- victims of such diseases. We join the other voluntary and professional associations in asking for an increase in the funding level of the NIADDK to at least $550 million for Fiscal Year 1985.

Why is this level of support for the NIADDK important to the patients with Paget's disease, and to their families and their physicians?

- Because only the NIADDK can effectively pursue the ongoing research into the causes and possible prevention of Paget's disease of bone, through its individual research grants and overall basic research programs.

- Because the NIADDK-sponsored clinical programs are vital to learning the impact of current medical therapies -- therapies developed in the past fifteen years with the support of this Institute -- on the long-term relief of symptoms and on slowing the progression of the disorder. These programs also lead to a better understanding of the natural history of the disorder.

- Because the NIADDK and the entire Department of Health and Human Services (DHHS) are the leaders in health communications between the researcher, the treating physician, and the lay public.

For those of you who are not familiar with it, Paget's disease of bone is a slow-progressing, debilitative, and crippling disorder in which the normal remodeling of the bone goes haywire. The rate at which old bone is resorbed away is dramatically speeded up. New bone is laid down in a haphazard and chaotic fashion. The resulting bone is larger but less compact and structurally less strong, and thus prone to fracture.

Bone pain and sensations of heat commonly are felt by Paget's patients who have active cases of the disease. In more severe cases, limbs may bow, the skull become enlarged, and numerous muscle and sensory disturbances may be experienced. Cranial nerve compression may cause hearing loss or ringing in the ears and may affect vision, swallowing, speech, balance, and other functions.

It is estimated that over three million Americans, or 3% of those over age forty, have Paget's disease of bone. This number is growing as the population ages. An additional factor would appear to be a predisposition to the disease within certain families. Few accurate statistics exist because the disease tends to elude detection until an individual has been afflicted for years. Figures available indicate that while between 50,000 and 75,000 people are being treated for their Paget's disease, probably ten times that many need treatment but are not receiving it. And as science uncovers more about the etiology and epidemiology of the disease, those numbers may increase accordingly.

Today, the small number of patients under treatment effectively puts Paget's disease of bone in the "orphan disease" category, according to recent DHHS guidelines. And Paget's disease has much in common with lower incidence disorders:

- o Few laypersons talk about or know anything about the disease. Information is difficult to obtain. One treating physician finds that many patients coming to his office for the first time suffer almost as much from the fear and the frustration of being uninformed and unable to find help as they sustain from their untreated symptoms.

- o Most physicians are unaware of recent developments in the treatment of Paget's disease. They learned about the disorder in a brief period during medical school, in which they were told that little could be done for the patient. Similarly, detection lags; often a correct diagnosis is not made because Paget's symptoms can be confused with those of arthritis and other diseases.

- o Limited funds are being made available for proprietary research. Pharmaceutical companies are not looking for new therapies because they are not seen as being able to generate a profit -- even though much work has already been done in other countries on some very promising compounds. Paget's disease is not a compelling disease, it seems; it is not a "killer disease" or one that afflicts children. In spite of the pain, disfigurement, and loss of the quality of life that sufferers endure, Paget's disease has not rallied a ground swell of public support for its eradication.

For these reasons, the Paget's Disease Foundation has joined the National Organization for Rare Disorders (NORD). Efforts are being made together to arouse public awareness and a sense of national responsibility to help those suffering from diseases that have long been swept under the national carpet.

We, collectively, look to the NIADDK and NIH for research leadership and support, of the same kind that produced major advances in past years. And for the essential communications which bring advances and new knowledge into the health care system. In 1985 this support will not be provided adequately by the private sector, either by industry or by organizations such as ours.

The Paget's Disease Foundation is one example of many groups, each representing a small part of the population. It is barely six years old, with an operating budget of under $100,000. Obviously the Foundation cannot contribute in any significant way to the financing of research. We know that government sponsorship can work, because Paget's disease victims are the beneficiaries of one of the recent medical success stories:

o After almost a century with no available treatment, several drugs were discovered which inhibit the bone resorption and effectively slow the progress of the disease. In some cases these drugs may even promote restoration toward normal bone architecture. Much of the work done in this country to explore the effects of these agents -- the hormone calcitonin, the diphosphonate disodium etidronate, and the cytotoxic agent mithramycin -- was done by physician-researchers and scientists working under grants from the NIADDK during the 1970's.

The investment of past support of NIH research programs has paid off. You and other members of Congress who made this investment possible are to be congratulated. We owe you a great deal of appreciation. But we also must urge you not to let this vital support diminish.

Appropriations voted by you today for the NIADDK are critical to tomorrow's realization of the postulations of current research:

- o An ongoing NIADDK grant is supporting research on the etiology of Paget's disease. Researchers may be isolating a slow-acting virus as the cause for the disease, thereby leading the way to its possible prevention through immunizing vaccines, not unlike the recent AIDS discovery.

- o Other studies under the General Clinical Research Program are reaping important information about treatment of the disease. Under this program, more resources are available to the physician-researcher than would be possible through individual grants.

These two research approaches together offer a great deal of encouragement to those who suffer these disorders and to those who must treat them.

In view of the rapidly rising costs of hospitalization and labor-intensive health care, just think what early diagnosis and effective treatment -- even preventive treatment -- would mean to all of society, as well as to victims of the disease. Think what a relatively few dollars invested today in research, in innovation, can mean tomorrow in terms of demands on the nation's economic resources.

Nor can we allow the role of the NIH in public education to be diminished.

The network of communications spearheaded by the NIH will in future years provide a vital service in disseminating new developments in research and treatment, so that they will be effective in helping patients as quickly as possible. Our Foundation looks to the NIADDK as well to foster interchanges between researchers and physicians, in seminars and conferences, to stimulate new or better-defined approaches to research.

At the present time, this Foundation's major focus is to educate the lay public and update health professionals on the diagnosis and treatment of Paget's disease. Our resources are strained attempting to reach the estimated three million people who are believed to have the disorder in one stage or another, and particularly the three quarter million who need treatment without delay.

In 1982 the NIADDK prepared a brochure, "Understanding Paget's Disease," in consultation with the Advisory Medical Panel of this Foundation. It is the only truly comprehensive piece on Paget's disease that has been written for the public, and has been an invaluable addition to the educational materials circulated by the Foundation.

We have worked with the NIADDK to publicize the availability of the brochure. As a result of our joint efforts, in 1983 the Paget's Disease Foundation responded to over 5,000 inquiries from the public. In addition, information materials have been supplied to numerous health agencies on state and local levels, hospitals, clinics, and individual physicians and patients.

To what avail? Excerpts from a letter sent by a patient to the Foundation this past December speak most eloquently:

> I want to thank you very much for the brochure on Paget's Disease I sent for & received latter part of October. They have been very useful to me & very interesting for which I & my family has learned & know more about the Disease which I have had for the past 12-13 yrs that I know of. Reading thru contents it has put my mind a little more at ease especially that now the Disease is treatable, at least that's a step ahead. I have been in a lot of pain from time to time during the years & worsens every time the siege returns & lasts for quite a few weeks. . .
>
> Through your suggestion in the Brochure I was able to make contact through the Medical Society with an Orthopedist who is familiar about the Disease & its treatment. After reviewing x-rays & my case I am now taking medication . . .
>
> Will try that out for awhile & hope it will have some good results at least relief & some freedom from pain.
>
> I will be 68 years of age on Dec. 18 & looking forward to a brighter future from the Paget's disease of the Bone. & hope the same for many, many others who are experiencing the same.

Letter From Roy H. Boyd, Chairman, Committee on Legislation, United Ostomy Association

April 24, 1984

Honorable Lowell Weicker, Jr.,
Chairman, Subcommittee on Labor
HHS - Education Appropriations
Washington, DC 20510

Dear Mr. Chairman:

The United Ostomy Association (UOA) is a member of the Coalition of Digestive Disease Organizations which is requesting your support in funding the health and human services programs.

The UOA has 650 chapters with over 50,000 members. This includes members in every state. We respectfully request that you support the recommendations of the Coalition for funding the Information Clearing House, the National Digestive Diseases Advisory Board, and basic research programs to prevent or cure digestive diseases.

The Information Clearing House will make information more readily available to assist in rehabilitating more than 1 million persons estimated to have had ostomy surgery (colostomy, ileostomy, or urostomy) as a radical cure for digestive diseases that include ucerative colitis, Crohns disease, diverticulitis, and cancer.

Most of our members have experience the disabling effects of a digestive disease that has been cured by surgery. Therefore, we will deeply appreciate all that you and your committee can do to cure such diseases or to rehabilitate those patients who must have ostomy surgers. We are especially concerned about the struggle that elderly ostomy patients are experiencing in paying for essential ostomy equipment in many States that lack medicaid/medicare reimbursements for such supplies.

This letter is to supplement the statements of our Coalition witnesses scheduled to appear before your committee on April 24,1984.

Sincerely yours,

Roy H. Boyd

Roy H. Boyd
Chairman, Committee on Legislation
United Ostomy Association

SUBCOMMITTEE RECESS

Senator Rudman. The subcommittee will now stand in recess until the call of the chairman.

[Whereupon, at 12:22 p.m., Tuesday, April 24, the subcommittee was recessed, subject to the call of the Chair.]

LIST OF WITNESSES, COMMUNICATIONS, AND PREPARED STATEMENTS

Page

Affeldt, David, assistant legislative counsel, Association of Retired Persons ... 49, 55
  Prepared statement ... 56
American Association of Colleges of Nursing, prepared statement ... 461
Anderson, Arden, M.D., chairman of the board, American Academy of Family Physicians ... 425
Apuzzo, Virginia M., National Gay Task Force ... 222
Association of American Medical Colleges, prepared statement ... 470

Babbitz, Matilda A., executive director, American Association of Occupational Health Nurses ... 96
  Prepared statement ... 97
Bailey, Laura, Maine Diabetes Control Project Advisory Committee, State of Maine ... 211
  Prepared Statment ... 211
Barlow, Charles F., M.D., chairman, mental retardation center directors; professor of neurology, Harvard University; neurologist and chief, children's hospital in Boston; and director, Children's Hospital Mental Retardation Research Center ... 350
  Prepared statement ... 351
Batson, Blair E., M.D., chairman, department of pediatrics, University of Mississippi Medical Center ... 382
  Prepared statement ... 385
Baumeister, Alfred A., Ph.D., director, John F. Kennedy Center; representing American Association on Mental Deficiency, American Academy on Mental Retardation, and American Psychological Association ... 368
  Prepared statement ... 369
Bellanti, Jacqueline R., chairman, National Coalition on Immune System Disorders ... 545
  Prepared statement ... 548
Bolan, Robert, executive vice president, American Diabetes Association; representing Christopher M. Saudek ... 666
  Prepared statement ... 668
Bourie, James G., director, national economic commission, the American Legion, prepared statement ... 132
Boyd, Roy H., chairman, committee on legislation, United Ostomy Association, letter from ... 716
Bradford, Dr. Robert, founder, the Committee for Freedom of Choice in Medicine, Inc. ... 265
  Prepared statement ... 266
Brent, Dr. Robert, chairman, department of pediatrics, Jefferson Medical College, Philadelphia, prepared statement ... 395
Busch, Elva, president, Connecticut Association of Home Anesthetists ... 407
  Prepared statement ... 409
Byrd, Dr. Benjamin F., professor, clinical surgery, Vanderbilt University ... 249
  Prepared statement ... 250

Page

Cantrell, Ralph G., commissioner, Virginia Employment Commission representing the Interstate Conference of Employment Security Agencies, Inc., prepared statement ... 226
Clark, Kemp, M.D., president, the Society of Neurological Surgeons, past president, American Association of Neurological Surgeons, chairman, Washington Committee for Neurological Surgery ... 510
  Prepared statement ... 511
Connors, Raymond A., president, Tuberous Sclerosis Association of America, prepared statement ... 520
Cooney, David M., president and chief executive officer, Goodwill Industries of America, prepared statement ... 103
Corn, Dr. Martin, president, Association of University Programs in Occupational Helath and Safety, director, Educational Resource Center for Occupatonal Health and Safety, school of hygiene and public health, Johns Hopkins University ... 179
  Prepared statement ... 181

Darden, Steven, chairman, Affiliation of Arizona Indian Centers, Inc., prepared statement ... 131
Deeb, Larry, C., M.D., children's clinic, Florida Department of Health and Rehabilitation ... 186
  Prepared statement ... 188
DeVito, Roberta, American Brittle Bone Society ... 565
  Prepared statement ... 569
Dirks, Harley M., consultant, Social Policy National HomeCaring Council ... 423
  Prepared statement ... 423
Durant, John R., M.D., member, public issues committee, American Society of Clinical Oncology ... 258
  Prepared statement ... 260

Egan, Paul S., deputy director, National Legislative Commission, prepared statement ... 132
Ewing, Dr. Larry L., professor, school of hygiene and public health, Johns Hopkins University, prepared statement ... 516

Fazio, Hon. Vic, U.S. Representative from California ... 27
  Prepared statement ... 30
Field, Dr. James B., chairman, National Diabetes Foundation ... 582
  Prepared statement ... 583
Fink, Jordan N., M.D., president, the American Academy of Allergy and Immunology ... 536
  Prepared statement ... 537
Fossedal, Ruth, president, Displaced Homemakers Network, Inc., prepared statement ... 137
Freeman, Dr. Richard B., head, nephrology unit, University of Rochester Medical Center, immediate past president, Renal Physicians Association ... 589
  Prepared statement ... 590

Gaines, John W., president, Teledyne Economic Development Co., prepared statement ... 116
Grace, Dr. Marcellus, dean, Xavier University School of Pharmacy ... 434
  Prepared statement ... 435
Greenfield, Dr. Wilbert, president, Virginia State University ... 1
  Prepared statement ... 10

Harris, James G., Jr., commissioner, department of human resources, State of Connecticut, prepared statement ... 167
Healy, Alfred, M.D., president, American Association for University Affiliated Programs for Persons with Developmental Disabilities ... 376
  Prepared statement ... 377

Page

Holverson, Harmon E., M.D., president, American Academy of Family Physicians 425
  Prepared statement 426
Hoyer, Leon W., M.D., chairman, medical and scientific advisory council, the National Hemophilia Foundation 324
  Prepared statement 325
Hudacs, Hon. John F., executive deputy commissioner of labor, New York Department of Labor 39
  Prepared statement 40
Humphreys, Robert, Esq., Washington counsel, Arthritis Foundation 595
  Prepared statement 596

Javits, Hon. Jacob K., former U.S. Senator from New York 475
  Prepared statement 480

Keller, Reed T., M.D., professor and chairman, department of medicine, University of North Dakota School of Medicine 661
  Prepared statement 662
Knapp, Albert Bruce, M.D., postdoctoral research fellow, Brigham and Women's Hospital and Harvard Medical School, representing the Dean Thiel Foundation, Cedar Grove, NJ 689
  Prepared statement 689
Kobell, Ruth E., legislative assistant, National Farmers' Union 62
  Prepared statement 63
Kone, Ann, executive director, Paget's Disease Foundation, prepared statement 711
Kurtz, Barbara H., ordained minister and student, University Gerontology Center, Wichita State University, prepared statement 110
Kushnick, Helen G., Samuel Jared Kushnick Foundation 214
  Prepared statement 215

Lamont-Havers, Dr. Ronald W., National Arthritis Advisory Board 602
  Prepared statement 603
Layman, Barbara H., president, the Asthma and Allergy Foundation of America 536
  Prepared statement 537
Legerton, Clarence W., M.D., chairman, Public Policy and Government Relations Committee 613
  Prepared statement 614
Lloyd, Douglas S., M.D., M.P.H. commissioner, department of health services, State of Connecticut 192
  Prepared statement 193

Markowitz, Milton, M.D., professor of pediatrics, associate dean for student affairs, the University of Connecticut, letter from 390
Marquardt, Robert L., Ph.D., chairman and president, Management and Training Corp., prepared statement 123
Martin, Donald B., M.D., Pennsylvania Diabetes Task Force 205
  Prepared statement 205
Matia, Barbara A., Scottsdale, AZ 609
  Prepared statement 612
McCarter, Katherine S., associate executive director, American Public Health Association 143
  Prepared statement 146
McCurdy, Paul R., M.D., chairman, public eduation committee, American Society of Hematology 318
  Prepared statement 319
Megida, Nathan, chairman, Bridgeport, CT, Private Industry Council representing Frank Cole, director of data processing, Travelers Insurance Co 84
  Prepared statement 85

Page
Miller, Roberta Balstad, executive director of the Consortium of Social Science Associations ... 150
  Prepared statement ... 152
Monaco, Grace Powers, J.D., national liaison chairperson, Candlelighters ... 282
  Prepared statement ... 285

National Association of Regulator Utility Commissioners, prepared statement ... 170
National Crushed Stone Association, prepared statement ... 141
Neal, William A., president, National Perinatal Association ... 442
  Prepared statement ... 443

O'Kieffe, Donald, M.D., member, legislative committee, American Society for Gastrointestinal Endoscopy ... 620
  Prepared statement ... 621
Oppenheimer, Edgar, assistant professor in pediatrics and neurology, Boston University School of Medicine and board member, Tuberous Sclerosis Association of America, prepared statement ... 522

Papp, John P., M.D., F.A.C.P., chairman, legislative affairs committee of the American College of Gastroenterology ... 626
  Prepared statement ... 627
Pessar, Arlene, R.N., executive director, Dystrophic Epidermolysis Bullosa Research Associaton ... 643
  Prepared statement ... 644
Plum, Dr. Fred, neurologist ... 475
  Prepared statement ... 486
Polivchak, Philip, president, Home Builders Institute, letter from ... 115
Prater, Dr. Oscar, vice president of administration, Hampton Institute ... 1
  Prepared statement ... 2

Regional Operations for Facilities Engineering and Construction Staff, region VII, letter from ... 466
Renda, Anthony, medical and scientific liaison, representing Nunzio Cazzetta, vice president, Cooley's Anemia Foundation ... 331
  Prepared statement ... 332
Rider, Dr. J. Alfred, Ph.D., president, Children's Brain Diseases Foundation ... 501
  Prepared statement ... 502
Rockwood, Dr. Charles A., Jr., president, America Academy of Orthopaedic Surgeons, prepared statement ... 700
Roosevelt, Hon. James, on behalf of the National Committee for Research in Neurological and Communicative Disorders ... 552
  Prepared statement ... 553
Ruben, Dr. Robert J., chairman, department of otolaryngology, Albert Einstein College of Medicine ... 495
  Prepared statement ... 496
Ryan, Dr. Thomas J., professor of cardiology, Boston University; and president-elect of the American Heart Association ... 343
  Prepared statement ... 344
Ryberg, Jacqueline W., R.N., M.A., CPNP, National Association of Pediatric Nurse Associates and Practitioners, prepared statement ... 457

Santo, Ron, honorary member, board of directors, Juvenile Diabetes Foundation International ... 652
  Prepared statement ... 654
Shannon, Dr. David T., president, Virginia Union University ... 1
  Prepared statement ... 7
Sherlock, Paul, M.D., chairman, National Digestive Diseases Advisory Board ... 681
  Prepared statement ... 682
Simmons, O.H., corporate secretary, MINACT, Inc., prepared statement ... 127
Simmons, Samuel J., president, National Caucus and Center on Black Aged, Inc., prepared statement ... 52

Page

Stern, Janet, executive director, South-West Neighborhood Health Center, Bridgeport, CT 399
  Prepared statement 400
Swomley, James A., managing editor, American Lung Association 309
  Prepared statement 310

Talbot, Timothy R., Jr., M.D., chairman of the board, Association of American Cancer Institutes and president emeritus, Fox Chase Cancer Center 289
  Prepared statement 289
Taylor, Peggy, legislative representative, American Federation of Labor and Congress of Industrial Organizations [AFL-CIO] 89
  Prepared statement 90
Teter, Harry Jr., executive director, National Coalition for Emergency Medical Services, prepared statement 235
Thomas, Patricia, legislative liaison, representing James M. Pierce, president, National Federation of Federal Employees 69
  Prepared statement 70
Trible, Hon. Paul S., U.S. Senator from Virginia 1
  Prepared statement 2

Vaughn, E. Darracott Jr., M.D., chairman, research committee, American Urological Association 560
  Prepared statement 561
Vodra, Richard E., president, Coalition for Health Funding 157
  Prepared statement 159

Wachacha, Arnold, JTPA director, Eastern Band of Cherokee Indians 75
  Prepared Statment 76
Wallace, Samuel B., medical researcher, U.S.A. health care practitioner, Brazil 274
  Prepared statement 276
Wanat, Dr. and Mrs. Francis E., Dystrophic Epidermolysis Bullosa Research Association of America, prepared statement 708
Weary, Dr. Peyton E., the American Academy of Dermatology, Inc. 631
  Prepared statement 632
Wertheimer, Wendy J., director of public and government affairs, American Social Health Association, prepared statement 236
Williams, John F., M.D., president, American College of Cardiology 301
  Prepared statement 302
Willig, Joyce, copresident, Connecticut chapter, American Liver Foundation, representing the American Liver Foundation, Cedar Grove, NJ 693
  Prepared statement 694
Wilson, Dr. Harrison, president, Norfolk State University 1
  Prepared statement 2
Wise, Jarrett M., RPA-C, past president, American Academy of Physician Assistants 447
  Prepared statement 448
Wolff, Sheldon M., M.D., on behalf of the Infectious Diseases Society of America 529
  Prepared statement 530

○